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Wise Up To Cancer - can it make a difference?

The final report on Wise Up To Cancer, a pilot community health initiative to improve cancer outcomes in Yorkshire



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1. The Wise Up To Cancer Initiative

Wise Up To Cancer (WUTC) is a Community Health Initiative funded by Yorkshire Cancer Research, with the intention to assess whether this type of initiative could contribute to the charity's regional strategy of improving cancer outcomes and its 10-year goal of achieving 2,000 fewer deaths from cancer every year by 2025. The initiative set out the following aims:

Primary aims

- A decrease in behaviours associated with cancer risk (e.g. smoking/obesity/inactivity).
- An increase in awareness of cancer signs and symptoms.
- An increase in the number of people taking part in the national screening programmes.
- An increase in signposting to other services (GP/smoking cessation/weight management programme/other services available).

Secondary aim

- Increase awareness of Yorkshire Cancer Research.

WUTC was piloted in communities in Leeds (largely in the west) and through pharmacies in the Wakefield District. These areas were chosen due to their high levels of deprivation and low screening uptake, high smoking prevalence and obesity levels and/or high Black, Asian and minority ethnic (BAME) populations. It was primarily aimed at people in the age groups eligible for the three national screening programmes (cervical, breast and bowel) and at anyone at a higher risk due to smoking or being overweight.

Members of the public who met the criteria were offered an assessment undertaken by a Community Health Educator (CHE) or a member of the Pharmacy team (a Pharmacy Champion). This took 15 to 30 minutes and consisted of talking through their lifestyle risk factors, assessing their knowledge of cancer signs and symptoms, recognising any current cancer signs and symptoms they are experiencing and identifying cancer screening programmes they are eligible for.

People were offered information relating to lifestyle and screening, signposted to health promoting activities or services and encouraged to commit to personal goals to make changes as appropriate. Thus WUTC was a targeted and personalised assessment which provided people with guidance about what they could do and the information they needed to be able to act on their goals. The target was to reach 2,000 people (1,000 in each setting) by the end of 2017.

CHEs are non-clinical local people who are trained to have 'healthy conversations' with members of the public. They are part of a long-standing team managed by Barca, a community organisation based in Armley,

west Leeds. They work with partner agencies to reach people at drop-ins, community venues and events.

In participating pharmacies at least two members of staff, who were already qualified to have 'healthy conversations,' were trained to become Pharmacy Champions and they were supported by Community Pharmacy West Yorkshire (CPWY). Both CHEs and Pharmacy Champions received specific training in WUTC.

Yorkshire Cancer Research produced a range of leaflets and a website to support the initiative: (www.yorkshirecancerresearch.org.uk/wiseuptocancer/).

This report was written in December 2017. In Leeds the initiative had been operational for nine months and been delivered in 34 different settings. In Wakefield the initiative had operated for eight months, CPWY have trained staff in 12 pharmacies, ten of which are actively delivering (see appendix 7 for full lists).

Data collection for the evaluation ended in mid-November, at which point 1,347 people had taken part in WUTC. However, the initiative will continue until the end of March 2018 to help reach the target of 2,000 people. By end March 2018, 1,855 people had taken part in WUTC (788 in pharmacy settings and 1,067 in community settings).

2. The evaluation

The evaluation combined quantitative and qualitative data collection methods, in order to assess to what extent the stated aims were being achieved whilst also gathering views on WUTC in order to understand what was/was not working. Throughout the implementation period monthly data reports were produced and a detailed interim report was produced three months into the initiative. The evaluation was conducted by a small team at Leeds Beckett University and received ethics approval by the University.

2.1 Questionnaire data collection

A critical part of this project is that the baseline WUTC questionnaire (appendix 1) fulfilled two functions – it both guided the conversation about cancer (with prompts for the CHEs and Pharmacy Champions delivering the initiative) and acted as the questionnaire through which baseline data was collected. This integration aimed to make the interaction smoother and avoid duplication.

The baseline questionnaire identified and recorded people's current lifestyle behaviours; knowledge of cancer signs and symptoms; experience of cancer signs and symptoms; and awareness of and engagement with, national screening programmes. Since it was anticipated that not everyone would agree to take part in the follow-up, this questionnaire also recorded perceived change in awareness of cancer signs and symptoms, likelihood of discussing any symptoms with a GP and whether they intended to make any behaviour changes as a result of the initiative.

Participants were asked, at the end of the initial assessment, if they consented to a follow-up questionnaire – with a prize draw as an incentive. If they consented, a follow-up questionnaire (appendix 2) was sent to them six to eight weeks later to assess progress towards goals.¹ Importantly the follow-up questionnaire was personalised to the participants' baseline data i.e. it used their first name, reminded them of the date and location where they completed WUTC and only asked questions about goals they had actually set, thus keeping the questionnaire short. Where relevant, participants were asked whether they had taken steps to:

1. change a lifestyle behaviour
2. speak to their GP about any cancer signs and symptoms they had identified in WUTC
3. complete any cancer screening that they were eligible for.

Participants were also asked for feedback on the initiative. These topics were assessed using both

multiple choice questions (e.g. lists of pre-set responses to state what action has been taken to work towards their goal) and open-ended questions to record further detail (for example to find out how lifestyle changes made them feel or what difficulties they had faced when trying to achieve their goals).

Making changes in behaviour is challenging, and expectations about what can be achieved through a short intervention like WUTC, within a relatively short time-frame, need to be realistic. The follow-up questionnaire therefore asked questions which identified the actions people had taken to work towards their goal.

The Stages of Change model (Prochaska and DiClemente 1983, appendix 3) is helpful as it illustrates how people move through various stages in the process of making change described as pre-contemplation (before thinking of doing anything); contemplation (thinking about making a change); preparation (getting ready to make a change); taking action and finally maintenance of that change. Relapse is possible at any point – so people may exit this cycle of change but also re-enter it at any point and on numerous occasions before the change they are making becomes habitual.

In assessing the effectiveness of WUTC, it is therefore important to recognise that a step towards change (e.g. a commitment to act) is part of the process and a measure of success as it signifies a step in the right direction. Similarly, progress made may be reversed at a later date.

2.2 Qualitative data collection

Interviews and focus groups were conducted with a range of stakeholders in order to ascertain their opinion of the intervention and capture more in-depth feedback on whether/how it worked. As can be seen in Table 1 initial data collection took place in the spring, in order to feed into the interim report (May 2017). Further data collection took place in the autumn, when the initiative was more established.

Service users were recruited via the follow-up questionnaire to take part in a telephone interview - they were offered a thank you of £20 of shopping vouchers. The intention was to interview ten people who had received the intervention in the community (with CHEs) and ten who had participated in a pharmacy. However only three of the latter took part, partly due to lower levels of follow-up in pharmacies (see later).

1. Participants could choose between receiving the follow-up by post to be completed manually and returned in a pre-paid envelope, or via e-mail (automated through the Snap survey software) to be completed electronically – those who received the follow-up via e-mail also received a reminder e-mail a week later (if the software showed that the e-mail had not been read then a separate e-mail was sent directly from the researcher to ensure they had received it).

Table 1. Interview and focus group participants

	Spring 2017	Autumn 2017	Total people
Service users - telephone interviews (Members of the public who took part in WUTC)	5 (community)	8 (5 community, 3 pharmacy)	13 (8 women, 5 men)
Community Health Educators from Barca - focus groups	4	2	6
Pharmacy Champions - telephone interviews	0 (too early)	10	10
Managers - face to face and telephone interviews	2	2 (same people - followed up)	2

2.3 Evaluation challenges

WUTC was a new and novel initiative and the process of developing it has resulted in many learnings for the delivery and evaluation teams. Key challenges are listed below:

- WUTC only engages with people for a short time and on one occasion. It would have been impractical and disproportionate to expect people to complete a baseline questionnaire separate from, and in addition to, the assessment itself. Having a tool which worked for both purposes (assessment and evaluation) was considered better, both for the person receiving WUTC and those delivering it. Producing this however was challenging and took a great deal of negotiation, hard work and goodwill on the part of all involved.
- The intervention required sophisticated use of survey software (SNAP). For example, the follow-up questionnaire needed to just contain information and questions relevant to the person's responses in the original baseline questionnaire. This needed to be done automatically due to the high numbers involved. In addition, community venues often did not have Wi-Fi so there needed to be a way therefore of collecting data and downloading this later. Resolving these issues was technically challenging but was successfully accomplished in time for the start of the project. This process of learning and development relied on having a member of staff capable of using the SNAP software to an advanced level.
- Pharmacies can only record patient data on their own database (PharmOutcomes) meaning they could not complete the online Snap Survey questionnaire. Depending on whether or not there was a computer in the consulting room, WUTC Champions used a paper version of the baseline questionnaire and later inputted data into PharmOutcomes. Anonymised data were then emailed from PharmOutcomes to Leeds Beckett University's researchers as an Excel file. As the format and order of data was inconsistent with that collected through Snap Surveys it required extensive editing using a sequence of macros that was developed. PharmOutcomes could only email patient contact details for follow-up to an NHS email account. Receiving permission to set up this account took until three months into the project.
- CHEs and Pharmacy Champions had to take on board a great deal of information and learn new technical skills for WUTC. Unsurprisingly therefore, in the early phase of the project data collection mistakes occurred. Whilst these became less frequent as the initiative progressed, small errors still remained particularly when paper questionnaires were used. Cleaning the data was therefore required throughout.
- One aim of WUTC was to signpost to services that could assist people making lifestyle changes. Unfortunately, the 'One You Leeds' lifestyle service (that was set up to do just that) was being recommissioned during the pilot, meaning there was limited service provision for approximately eight weeks. This is likely to have impacted on the lifestyle changes people made.

3. Delivery of the initiative

3.1 Location of delivery

WUTC was delivered in two areas – Leeds (primarily the west) by Barca Leeds and in Wakefield by Community Pharmacy West Yorkshire (CPWY).

Barca Leeds is based in Bramley but also works in Armley, Kirkstall and Hyde Park. These areas make up three of the nine most underprivileged wards in the City of Leeds. Ethnicity is predominantly White British with a significant proportion of Eastern European people in Bramley, Armley and Kirkstall. In Hyde Park there is also a substantial proportion of South East Asian families.

Large parts of these areas have social housing and the residents are affected by issues surrounding unemployment and/or low income. There are also higher than national averages in substance misuse, domestic violence, mental health and general health issues with low screening uptakes and high rates of smoking and alcohol use.

The areas are served by small town centres with shops/shopping centres with supermarkets and good local transport links. There are 'One Stops' in public buildings such as libraries providing advice on housing and welfare.

WUTC was delivered in west Leeds at 34 community venues on 64 occasions. Venues varied widely and included community groups, community centres, within the workplace, local events in parks and shopping centres (appendix 4). Whilst some venues mainly attracted people from the targeted area, the use of other venues e.g. workplaces, Headingley Stadium and popular festivals attracted people from a wider geographical area, although most participants were from the Yorkshire region (appendix 5).

In Wakefield, ten pharmacies were selected to be part of WUTC, from the 19 which applied. These are located in high areas of deprivation, with high smoking rates and where cervical, breast and bowel screening uptake is below the national average (as determined by the WUTC project group). The population covered by these pharmacies is mainly White British.

Pharmacies were asked to express an interest in delivering the WUTC pilot. They were selected based on the following criteria; willingness to put forward at least two members of the team to become Pharmacy Champions, previous good delivery of services (such as flu and blood pressure monitoring) and their response as to why the pharmacy should be selected for the project.

There were some changes to the pharmacies involved during the pilot – two withdrew (one in June and one in December), whilst two others joined in August (appendix 6). Similar to the community settings, the geographical location of participants deviated from the

target area although participants were mostly from the Wakefield area and wider Yorkshire region (appendix 5).

On four occasions individuals completed the baseline questionnaire twice (on different days). In order to ensure validity, these were removed from the dataset.

3.2 The staff

Seven CHes delivered WUTC in community settings. These comprised of two men and five women, with an age range from 20 to 50 years. Ethnicity was diverse, including White British, Asian and Black African.

Across the pharmacies that delivered WUTC, 47 staff (a mix of Pharmacists, Pharmacy Managers, Dispensing Assistants and Counter Staff) received training from the pharmacy co-ordinator. Five of these were male, with an age range from early 20s to mid-50s. Ethnicity was predominantly White British, reflecting the ethnic population of the area.

3.3 Uptake of WUTC

In community settings uptake increased during the summer months (Figure 1), mainly due to large events at Kirkstall Festival and at Headingley Stadium. Uptake was slower after the summer, due to staff turnover, illness, a lack of large events to attend and poor weather making outside locations less favourable places to converse. In pharmacies, WUTC started a month later with a fairly linear uptake over the pilot period.

3.4 Recruitment to follow-up

Out of the 1,347 participants, 931 (69%) agreed to receive the follow-up questionnaire (Table 2). Recruitment to follow-up was lower within pharmacies compared to community settings (48.1% vs 86.5% of participants). 576 (62%) of those who consented to follow-up opted to receive an email, the remainder opting for post. This was higher in community settings (70.5% of those who agreed to follow-up provided an email address) compared to the pharmacy setting (43.2% equivalent figure). The reasons for these differences are not entirely clear but are discussed in the qualitative findings later on.

As of 14th Nov 2017, 763 follow-up questionnaires had been sent (as the 6-8 week time period had been reached) and out of those, 168 (22%) had been completed (Table 2) with a similar response rate across the delivery settings. The response rate was greater via the electronic method which can be attributed to the email reminders sent (Table 2).

A review of the follow-ups completed electronically showed that 86% of those completions were split equally between smartphones and tablets, with desktop/laptop computers the least used format.

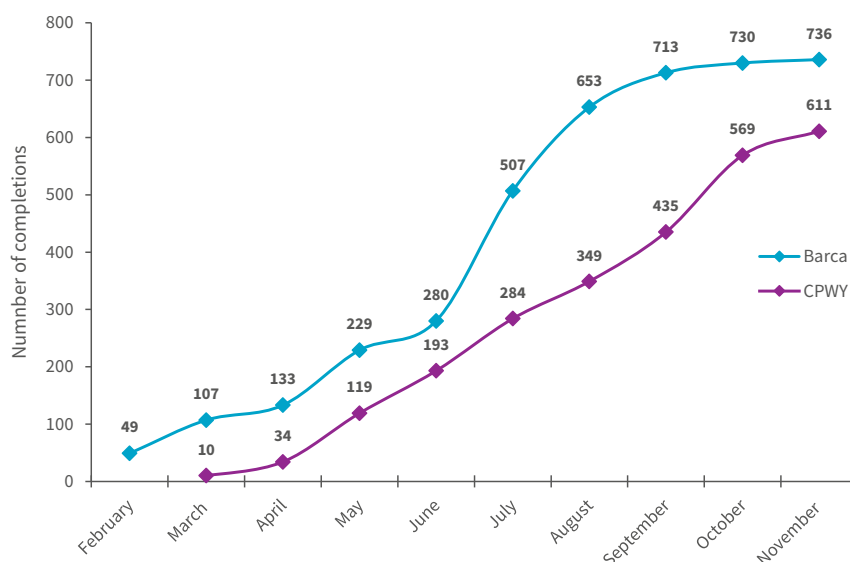


Figure 1. Number of WUTC participants completing the pilot

Table 2. Recruitment to follow-up and engagement

	All settings	Barca	Pharmacy
<i>Baseline</i>			
Participated as of 14th Nov	1,347	736	611
Consented to follow-up (% of participants)	931 (69.1)	637 (86.5)	294 (48.1)
Consented to providing email (% of all consenting to follow-up)	576 (61.9)	449 (70.5)	127 (43.2)
Incorrect/insufficient follow-up details (% of those consenting)	27 (2.9)		
<i>Follow-up</i>			
Sent follow-up as of 14th Nov	763	566	197.0
Withdrew from follow-up (% of those sent)	3 (0.4)		
Completed follow-up (% of those sent)	168 (22.0)	125 (22.1)	43 (21.8)
Paper follow-ups completed (% of sent by paper)	40 (14.7)		
E-mailed follow-ups completed (% of e-mailed)	128 (26.1)		
Completed after 1 Snap email (%)	60 (46.9)		
Completed after 2 Snap emails (%)	43 (33.6)		
Completed after a further direct email (%)	25 (19.5)		

3.4.1 Prize draw

Participant ID numbers of all those who completed the follow-up questionnaire and consented to be included in the prize draw were entered into an online random number generator.²

Eight numbers were selected by the tool (1 x £100 voucher, 2 x £50 voucher and 5 x £20 voucher) and the vouchers were sent in the post via recorded delivery.

2. <https://www.miniwebtool.com/random-number-picker/>

4. Questionnaire findings

A summary of key findings at baseline and follow-up are presented in this section - a detailed analysis of all data collected at baseline and follow-up can be found in appendices 7 and 8. All baseline data covers the period up to 14th November 2017.

4.1 Participants

A total of 1,347 people completed the initiative (736 through community settings and 611 through pharmacies). Of the 1,318 who provided their gender, the balance was 34% men and 66% women (Table 3). Ethnicity was provided by 1,341 people and was predominantly White British (87%). Age was provided by 1,339 people and was slightly older for men than women (55 years vs. 51 years).

Criteria for participation included eligibility for screening – therefore a higher proportion of women, particularly younger women, is to be expected as they are eligible from 25 years (for cervical screening) whereas men are only eligible from 60 years (for bowel screening). However, men (particularly in the areas targeted) are more likely to engage in unhealthy lifestyle behaviours (e.g. smoking or being overweight) which would also make them eligible for participation and men aged over 50 who have had a persistent cough are eligible for a chest x-ray.

The type of participants completing WUTC was somewhat different between the two settings, with west Leeds community settings engaging a greater proportion of men, slightly younger participants, and more ethnically diverse participants compared to pharmacies (Table 3).

4.2 Lifestyle behaviours

Out of all the respondents who completed the baseline questionnaire, 948 (70%) set at least one lifestyle-related goal, though it was possible to set more than this:

- 704 people (52% of all participants) set a weight management/diet goal

- 418 people (31% of all participants) set a physical activity goal
- 93 people (7% of all participants) set a goal to reduce or abstain from alcohol
- 166 people (12% of all participants) set a goal to reduce or stop tobacco use
- 29 people (2% of all participants) set a specific 'other' lifestyle-related goal.

471 of those people (50%) were signposted to a support service.

In the follow up questionnaire it was revealed that a further nine (female) participants, who had not set a goal at baseline later decided to make lifestyle changes. These mainly related to fitness, weight loss and/or eating more healthily but also included seeking medical advice, attending breast cancer screenings and using adequate sun protection.

4.2.1 Weight and diet

Baseline

Prevalence of unhealthy weight and diet

Self-reported, or measured, height and weight data were obtained from 995 people (74% of all participants) which included 359 men (80%) and 636 women (73%). Of those, over half had a BMI that was above a normal or healthy weight (Figure 2) which was more common among men [240 men (67% of those measured) vs. 386 women (61%)].

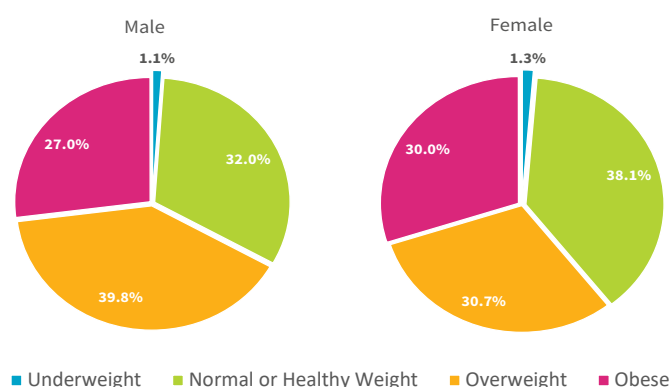


Figure 2. Percentage breakdown of BMI category by sex

Table 3. Participant sex and age across the two settings

	All settings	Community settings	Pharmacies
Number of participants	1,347	736	611
Number of men (%)*	447 (34%)	266 (38%)	181 (30%)
Number of women (%)*	871 (66%)	442 (62%)	429 (70%)
Age (years)			
Range	18 to 90	18 to 90	19 to 90
Mean (±SD)	51.4 (±17.1)	49.5 (±17.4)	53.8 (±16.5)
Ethnicity			
Number of White British (%)*	1,161 (87%)	576 (79%)	585 (96%)
Number of Other Ethnicity (%)*	180 (13%)	156 (21%)	24 (4%)

* Percentage of those who provided the information

Of the 1,333 respondents to the question ‘Are you a healthy weight at the moment?’ 629 (47%) said they were and this belief was more common among men than women (55% of male respondents vs. 43% of female respondents). Of the 470 people (188 men and 282 women) who thought they were a healthy weight and also provided height and weight data, over half had a BMI that was overweight or obese. This was more prevalent amongst men (50% vs. 33% of women).

Of interest, is that overweight was more prevalent among those completing WUTC through pharmacies in Wakefield (67% vs. 61%). Similarly, obesity was more common in pharmacies, however in both settings, prevalence was higher than the estimated proportions of obese adults across those areas (Table 4) (PHE, Cancer in Yorkshire and the Humber 2016 report).

Table 4. Reported prevalence of obesity vs. estimated for the local areas

	Obese (%)
Community settings	26.4
Estimated for Leeds	19.5 to 22.6
Pharmacies	33.7
Estimated for Wakefield	22.6 to 25.7

People ate red meat on average 2.5 times a week, ranging from 0 times to 17. Wholegrains were eaten on average 4.8 times a week (therefore not every day), whilst on average 3.6 portions of fruit and vegetables were eaten a day (less than the recommended five a day) (Table 5), although 452 people (34%) ate five or more portions per day. Some people did not eat any wholegrains or fruit and vegetables. Women tended to eat less red meat and more fruit and vegetables but their wholegrain consumption was similar to men’s.

Consumption of fruit and vegetables and wholegrains was generally similar between community settings and pharmacies, however red meat consumption was typically greater within participants recruited through pharmacies (3 vs. 2 portions).

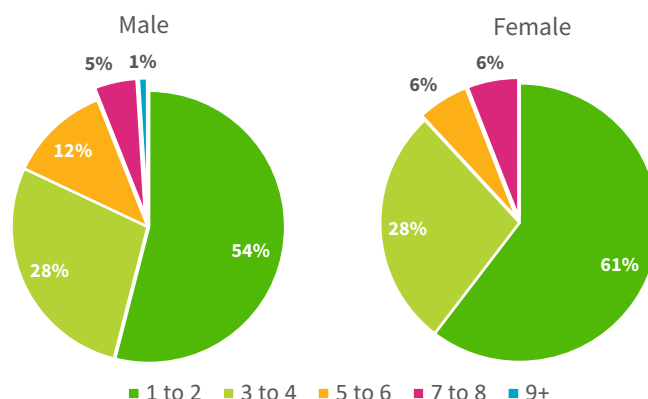


Figure 3a. Percentage breakdown of red and processed meat consumption (portions per week) by sex

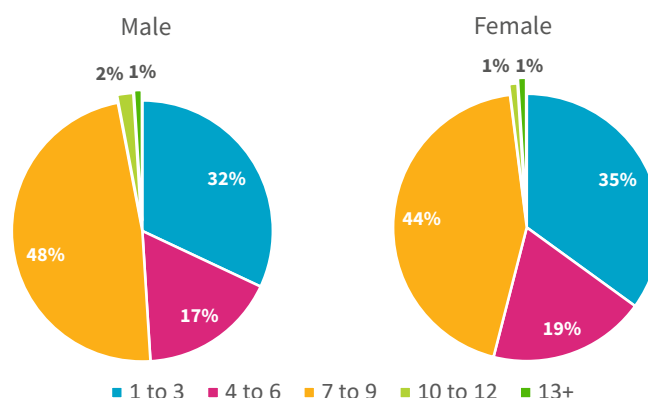


Figure 3b. Percentage breakdown of wholegrains consumption (portions per week) by sex

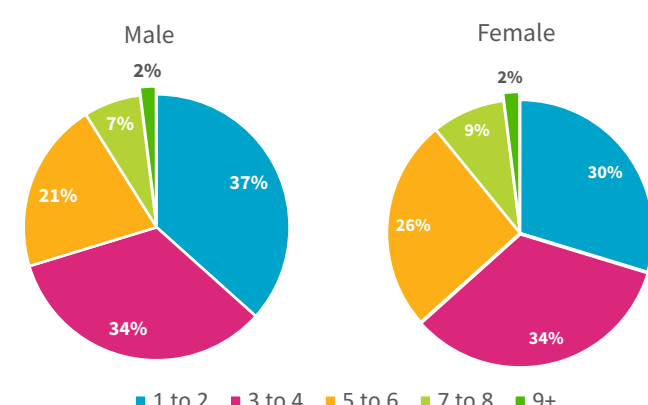


Figure 3c. Percentage breakdown of fruit and veg consumption (portions per day) by sex

Table 5. Dietary habits of men and women participating in WUTC

	All participants	Men	Women
<i>Red meat (portions per week)</i>			
Range	0 to 17	0 to 14	0 to 17
Mean (±SD)	2.5 (2.0)	2.8 (±2.1)	2.4 (±1.9)
<i>Wholegrains (portions per week)</i>			
Range	0 to 32	0 to 15	0 to 32
Mean (±SD)	4.8 (±2.9)	5.0 (±2.9)	4.7 (±2.9)
<i>Fruit and veg (portions per day)</i>			
Range	0 to 12	0 to 10	0 to 12
Mean (±SD)	3.6 (±2.1)	3.3 (±2.0)	3.7 (±2.1)

Table 6. Progress of participants who had set a weight and/diet goal

	Weight and/diet related goal
Set a goal at baseline	704
Completed follow-up(*)	104 (15%)
Answered follow-up question	97
Taken positive action (†)	88 (91%)
Lost weight (†)	37 (38%)
Trying to be more active in everyday life (†)	56 (58%)
Eating more fruit and vegetables (†)	53 (54%)
Eating more wholegrains (†)	34 (35%)
Not taken any action (†)	9 (9%)

* % of those setting a goal

† % of those answering the follow-up question

Goals set

A total of 704 people (52% of participants) set a goal to either specifically reduce their weight and/or to eat a healthier diet which may help to reduce weight, with 201 of these people (29%) setting both goals. Of the 642 people who had been classed as overweight or obese (BMI>24.9), 424 (66%) had set one or both goals (including 133 men and 279 women). However, whilst men were more likely to be overweight they were less likely to set a goal relating to weight and diet (72% of overweight women set a goal compared to 55% of overweight men).

Signposting to services

Of the 704 people setting a goal, 300 (43%) were signposted to weight management services, which was a similar proportion for men and women. Of the 424 overweight or obese people who had set a goal, 209 (49%) were signposted. Signposting of overweight women was slightly greater than for overweight men, with around 50% of overweight women setting goals being signposted to services (vs. 46% of overweight men setting goals).

Follow-up

Progress with weight and diet goals

104 of those who had initially set a weight and/diet goal, engaged in the follow-up, although only 97 of those answered the progress question. Of those, 88 (91%) had taken positive action (Table 6), with many losing weight, making positive changes to their diet and increasing physical activity.

Six of these people had contacted weight management services – one of these felt *‘More confident in managing my weight and diet following appointment with dietician.’*

Impact of changes

Some respondents stated that weight loss and changes to their diet had made them feel better:

‘[I find it] a little easier to move around, I have more energy and have a slimmer waistline.’

‘[It] has helped lower my back pain so less painkillers needed. Better bowel movements because of new diet and less medication.’

‘I lost 2 kg. Just feel proud of myself.’

For one woman, changing her eating habits resulted in her having *‘More energy, so picking my boys up from school I don't mind staying at the park playing ball/tennis with them.’*

One other person commented, *‘Although the changes I have made are small it has without a doubt helped me become more aware of what items I choose to cook with and buy from the supermarket. I feel slightly more confident in my ability to make bigger changes with time.’*

4.2.2 Physical activity

Baseline

Prevalence of inactive lifestyle

On average, both men and women stated they were physically active (completing at least 30 minutes of exercise/activity) for four days per week, below the UK guidelines (five days per week). 49% of males and 51% of females completed 30 minutes of exercise on less than five days per week. Completion of 30 minutes of exercise on less than five days per week was more common among pharmacy participants in Wakefield (56% vs. 44% for community participants).

Goals set

In total, 418 people (31% of all participants) set a goal to increase their physical activity. This was slightly more common among women (33% of those women vs. 27% of those men), which is positive considering that women were slightly less active.

Of those 658 people who were active on less than five days per week, 273 (49%) set a goal to increase their physical activity (38% of those men vs. 43% of those women), demonstrating that goals are being targeted according to current lifestyles.

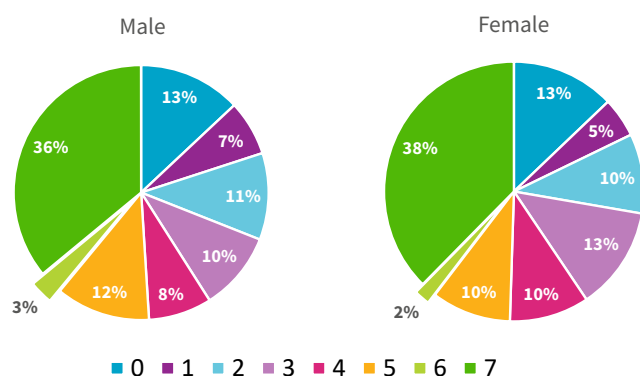


Figure 4: Percentage breakdown of number of days in week where 30 minutes of physical activity completed by sex

Signposting to services

Of the 418 people setting a physical activity goal, 206 (49%) were signposted to physical activity services, which was similar among both men and women. Of the 273 people classed as inactive who set a goal, 135 (50%) were signposted to a service which was similar among both men and women.

Follow-up

Progress with physical activity goal

66 of those who had initially set a physical activity goal, engaged in the follow-up and 65 of those answered the progress question. Of those, 56 people (86% of respondents) had made some progress towards achieving their goals (Table 7), with most progress focused around people trying to be more active in their everyday lives (e.g. walking or cycling more or using the stairs instead of lifts). Five of those people had contacted local physical activity services.

Impact of changes

Many commented that they had more energy and/or felt less tired.

'[I have increased] my gym activity to include more cardio and I feel that I have more energy.'

'[I am] more mentally alert.'

'My swimming stamina has increased.'

One person expressed a sense of achievement: *'It's a good feeling walking nearly seventy thousand steps in a week, before I was lucky to get five thousand daily.'* and for another, improving fitness seemed to result in improved confidence and wellbeing: *'I feel better mentally since beginning to exercise. I don't feel as low in mood and it gives me an opportunity when exercising to be with my own thoughts.'*

4.2.3 Alcohol consumption

Baseline

Prevalence of alcohol consumption

At baseline, approximately 912 people (68%) stated that they consumed alcohol which included 336 men (75% of all men) and 558 women (64% of all women). Frequency of alcohol consumption was typically higher among men with 21% of male drinkers stating that they drank alcohol four or more times per week (vs. 9% of female drinkers) and men were more likely than women to drink 7+ units on each occasion (30% vs. 22% of male and female drinkers respectively). Almost one quarter of drinkers engaged in binge drinking (6 units or more) at least weekly, with men almost twice as likely as women (32% of male drinkers vs. 19% of female drinkers).

In general, participants completing WUTC through pharmacies consumed alcohol more frequently and in greater quantities compared to those completing in community settings, but were less likely to engage in binge drinking.

Goals set

In total, 93 people (including 41 men and 49 women) set a goal related to alcohol use (10% of all drinkers).

Signposting to services

Of the 93 people setting a goal, 28 (30%) were signposted to alcohol support services (34% of those males and 27% of those females who set a goal).

Table 7. Progress of participants who had set a physical activity goal

	Physical activity goal
Set a goal at baseline	418
Completed follow-up(*)	66 (16%)
Answered follow-up question	65
Taken positive action (†)	56 (86%)
Trying to be more active in everyday life (†)	45 (69%)
Attended a supervised physical activity service (†)	12 (18%)
Started their own physical activity programme (†)	15 (23%)
Not taken any action (†)	9 (14%)

* % of those setting a goal

† % of those answering the follow-up question

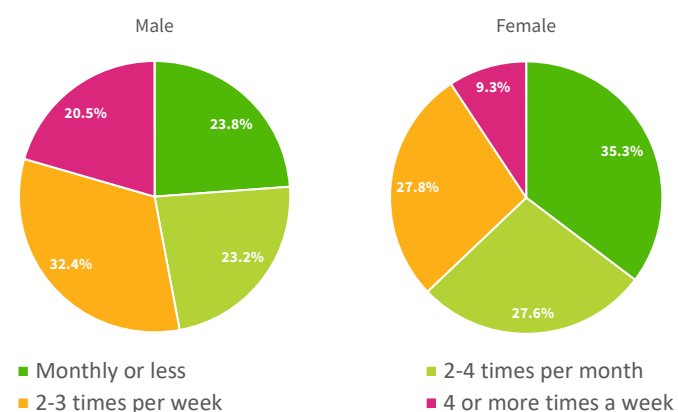


Figure 5a: Percentage breakdown of alcohol consumption by sex

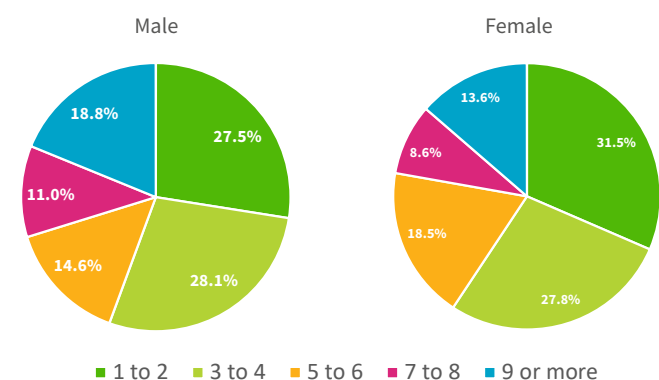


Figure 5b: Percentage breakdown of number of units of alcohol consumed on each occasion by sex

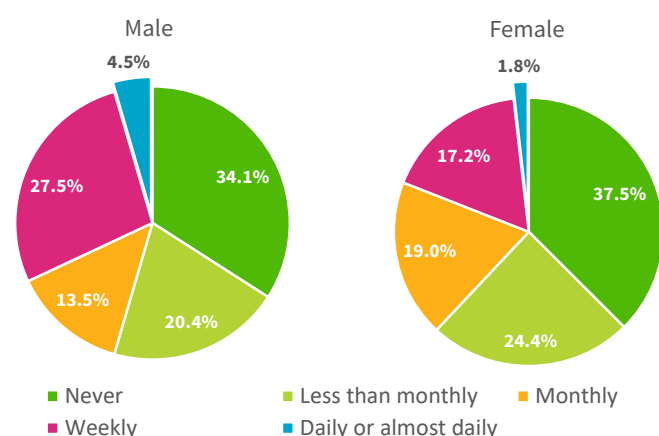


Figure 5c: Percentage breakdown of frequency of binge drinking (6 or more units on one occasion) by sex

Follow-up

Progress with alcohol consumption goal

17 of those who had initially set an alcohol goal, engaged in the follow-up and 16 of those answered the progress question. Of those, 12 people (75% of respondents) had made some progress towards achieving their goals (Table 8), with most reducing their alcohol consumption. One person had contacted and made an appointment with local services.

Impact of changes

One person originally set a goal to 'stay sober' and at follow-up they stated that they had since abstained from alcohol. Another commented '*I didn't really drink that excessively but have cut down having a few glasses of wine during the week. I do feel much better for it.*'

4.2.4 Tobacco use

Baseline

Prevalence of tobacco use

322 people (24%) currently smoked which included 120 men (27% of all men) and 196 women (23% of all women). Men were most likely to smoke on a daily basis (22% vs. 20% of female smokers). Only 45 people (3%) currently used smokeless tobacco and prevalence was similar for men and women.

Prevalence of smoking was somewhat greater among those participants completing WUTC through pharmacies in Wakefield than community settings in Leeds (27% of all participants vs. 19% of all participants). For Leeds, this was similar to the estimated proportions of adult smokers across Leeds (a range of 17 to 20.1%), but prevalence in Wakefield was much greater than the estimated proportions of adult smokers across Wakefield (a range of 20.1% to 23.2%) (PHE, Cancer in Yorkshire and the Humber 2016 report).

Goals set

In total, 166 people (49% of both male and female tobacco users) set a goal relating to tobacco use.

Table 8. Progress of participants who had set an alcohol consumption goal

	Alcohol consumption goal
Set a goal at baseline	93
Completed follow-up(*)	17 (18%)
Answered follow-up question	16
Taken positive action (†)	12 (75%)
Cut down alcohol consumption(†)	11 (69%)
Given up alcohol (†)	1 (6%)
Not taken any action (†)	4 (25%)

* % of those setting a goal

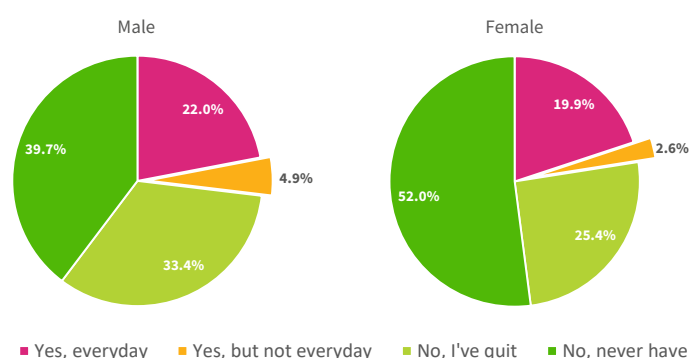
† % of those answering the follow-up question

Table 9. Progress of participants who had set a tobacco use goal

	Tobacco use goal
Set a goal at baseline	166
Completed follow-up(*)	18 (11%)
Answered follow-up question	18
Taken positive action (†)	13 (72%)
Cut down on smoking tobacco (†)	8 (44%)
Given up smoking (†)	4 (22%)
Not taken any action (†)	5 (28%)

* % of those setting a goal

† % of those answering the follow-up question

**Figure 6: Percentage breakdown of smoking status by sex**

Signposting to services

Of the 166 people setting a goal, 118 (71%) were signposted to services which included 44 men (73% of those men setting a goal) and 71 women (69% of those women setting a goal).

Follow-up

Progress with tobacco goal

18 people who had initially set a tobacco-related goal completed the follow-up questionnaire and all answered this question. Of those, 13 people (72%) had made some progress towards achieving their goal (Table 9), with over half of all respondents either cutting down or quitting. Two had contacted a support service and one of these people had attended the service.

Impact of changes

One person reported that they previously tended to smoke only 'When also drinking alcohol/socialising.' but since the WUTC intervention, this person no longer smoked socially in this way. Another commented '[I] can breathe a lot better now I've stopped smoking and started exercising.'

4.2.5 Other goals

Baseline

Goals set

At baseline, 29 people (2% of all participants) set a lifestyle goal outside of those suggested within WUTC. Most wanting to improve sleep quantity and quality but other goals set included registering with a GP, using more sun protection, entering employment and staying sober.

Signposting to services

Three people were signposted for support with their 'other' lifestyle goals - two to their GP and one to their local job centre.

Follow-up

At follow-up, the three participants who set goals around improving sleep routines report going to bed earlier, or aiming to be in bed by a certain time, and trying to get 7 to 8 hours of sleep. In addition, one person mentions striving to be more organised at home after work by, for example, 'Making lunch for the next day after having dinner therefore not making it at midnight.' Avoiding, or keeping time spent playing games online to a minimum, was another form of action taken towards this goal.

One person has sought medical advice for 'familial cancer' as a step towards achieving better sleep, as 'My father is suffering due to cancer at the moment for the third time.' Another participant, who also set out to reduce her stress levels, is now eating healthily and doing regular exercise in an effort to achieve this goal.

4.2.6 Barriers to lifestyle changes

32 participants who had not yet made any lifestyle changes provided a number of reasons for this:

- Health or medical reasons - injury or recovering from an operation, being on medication and 'Feeling poorly.' was preventing several participants from doing exercise.
- Lack of time - competing demands of work, 'The long hours and shift patterns.' and other life commitments, such as caring for grandchildren in school holidays, or simply 'Day to day things that get in the way.'
- Low motivation – self-professed laziness, and tiredness affected some people's motivation or simply not acknowledging the importance of making changes: '[I don't] feel at risk, nor am I overweight, so I guess knowing that I'm "safe" is not pushing me enough.'
- Other - A few people mentioned that the timing is not right for them due to current life situations such as moving house. One participant felt that their age (75) made exercise feel difficult and another reflected on the challenge of trying to break existing lifestyle habits: '[It's] difficult to change established patterns of eating.'

4.2.7 Summary

The high prevalence of overweight (63% of those providing data), inactivity (not typically meeting UK guidelines), smoking (24%) and sub-optimal consumption of fruit and vegetables (less than five portions a day) confirms that WUTC was successful at targeting people who may have an increased risk of developing cancer. Furthermore, prevalence of obesity in both locations was higher than estimated for those areas and prevalence of smoking was higher in pharmacy participants than estimated for that area. Those completing WUTC through pharmacies were more likely to smoke, be overweight and inactive compared to participants in Leeds.

WUTC was successful in encouraging a total of 948 people (70%) to set at least one lifestyle-related goal and of these, 471 (50%) were signposted to a support service. Furthermore, it successfully encouraged those at greatest risk to set lifestyle-related goals, with 66% of overweight participants setting a goal related to weight and/or diet (50% of these signposted to services), 49% of inactive people setting a goal to increase physical activity (50% of these signposted to services), and 49% of smokers aiming to cut down or quit (71% of these signposted to services).

Around three quarters of those at follow-up who had aimed to make lifestyle changes had taken positive steps – the most successful were those who had intended to change their diet and/or lose weight (91% of respondents had taken positive action and 37% of respondents had lost weight) and those who intended to become more physically active (86% of respondents had taken positive action). Similar positive results were observed for alcohol with 75% of respondents taking positive action and with tobacco use with 72% of respondents having taken positive action – one person had given up alcohol completely and four people had quit smoking.

Barriers to change seemed to focus around making changes to diet and physical activity, with common barrier including poor current health, lack of time or lack of motivation, which highlights the importance of signposting to services who may be able to provide specialist support to overcome these.

The findings overall demonstrate that WUTC has a high level of success in changing lifestyle behaviours and encouraging the use of support services.

4.3 Assessment of cancer awareness and encouraging early diagnosis

Baseline

Cancer awareness

Of the 1,297 participants who were asked about their awareness of cancer signs and symptoms, 1,215 (94%) could name at least one, and awareness was generally greater among pharmacy participants. On average, people were able to list four – however men's awareness was approximately half that of women's (Figure 7). The most commonly known symptom was a lump or swelling. Five people thought that cancer could have no signs or symptoms (response of 'nothing'). Additional signs and symptoms stated by 25 participants (not stated on the original tick list) included bloating, breathlessness and breast changes.

Experience of cancer signs and symptoms

A total of 640 people (47%), including 211 men (41% of all men) and 420 women (46% of all women) stated that they had recently experienced a sign or symptom of cancer, with 'feeling more tired than usual for some time', 'breathlessness' and 'a cough that has lasted for three weeks or more' being the most common (~35% of those participants) and were more common among women. 88 men (20% of all men) had experienced signs and symptoms of prostate cancer and 51 women (6% of all women) had experienced signs and symptoms of cervical cancer.

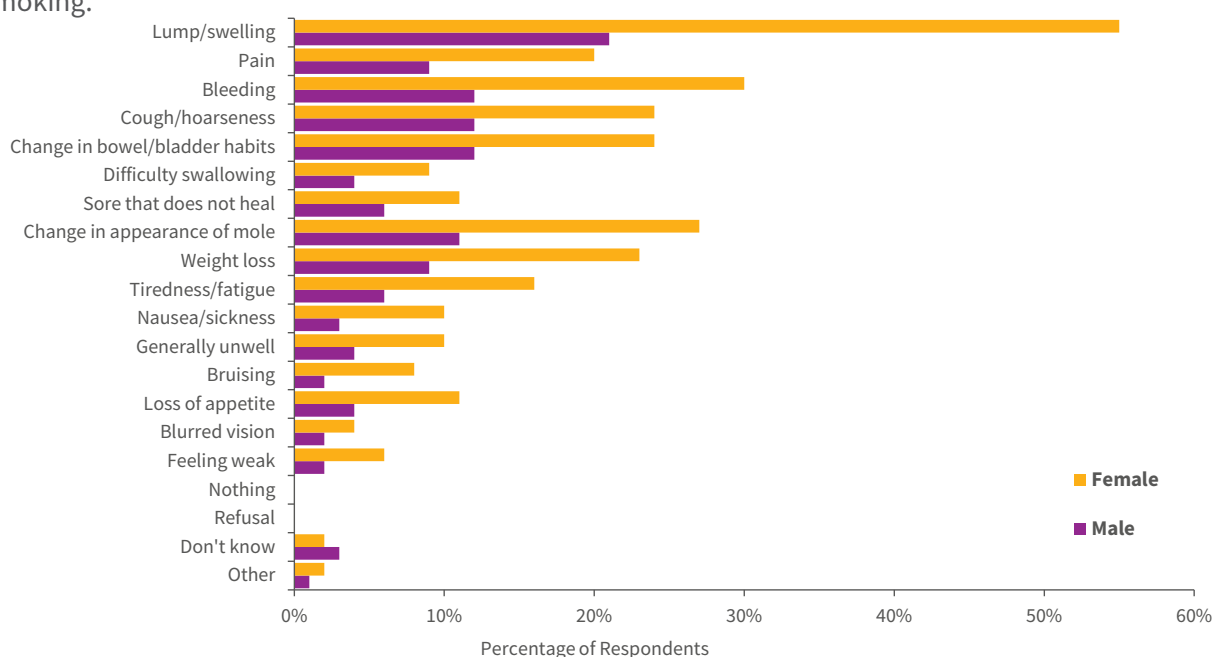


Figure 7. Awareness of cancer signs and symptoms across men and women

Prevalence of current symptoms was greatest in pharmacy participants, with over half having experienced one or more of the listed signs/symptoms.

Goals set

468 people had consulted with their GP about their signs and symptoms (73% of those experiencing symptoms), however of the 172 who hadn't (including 78 men and 92 women), 70% of those men and 56% of those women said they aimed to speak to their GP following WUTC.

Follow-up

Progress with goals

Of those completing the follow-up, 24 had previously set a goal to discuss their signs and symptoms with their GP and 9 of these had since done so (38%).

4.3.1 Reasons for not contacting a GP about signs and symptoms

Of those who hadn't consulted their GP, four said their symptoms had gone, and two said they hadn't been able to get a convenient appointment.

Some participants felt it was not relevant to consult their GP – that there was no need, or they did not feel it was a priority *'I'm ashamed to say it doesn't feel important enough, or perhaps more accurate to say "bad enough" yet - I know this is a bad attitude!'* In one case, a participant explained that she is going to monitor her situation for a while first: *'My signs & symptoms are not as severe or prominent as previously mentioned in the questionnaire so I'm seeing how I get on for now before contacting the GP.'*

Other people confirmed that they had already spoken to their doctor prior to participating; whilst others noted that they have not yet got around to it, but mean to do so. For one woman it was a combination of these reasons: *'Time is the main reason - caring for a disabled husband et cetera. Also the fact that I am overweight is the main cause of breathlessness when walking uphill or when rushing about, which I do a lot.'*

4.3.2 Summary

In summary, 94% of people knew at least one of the common signs and symptoms of cancer, particularly a lump/swelling, however women's awareness was almost double that of men's across all signs and symptoms. 73% of those people experiencing signs and symptoms had consulted their GP and of those who had not, 70% of those men and 56% of those women said they would do so. At follow-up, over a third of respondents who had initially planned to consult their GP had done so – some had not because their symptoms had disappeared, they were not able to get an appointment or did not think it was a priority.

4.4 Engagement with cancer screening

Baseline

Eligibility and goal setting

947 (70% of all participants) were eligible for any of the four screening programmes discussed (cervical, breast, bowel and chest x-ray) and 69 women (7.7%) were eligible for all three national screening programmes (cervical, breast and bowel).

179 screening goals were set across 162 people (Table 10), mainly among women (131 women vs. 29 men) which is likely due to women being eligible for multiple screening programmes across the lifespan.

Follow-up

Progress with goals

At follow-up, a total of nine screens had been completed which was 35% out of the 26 goals that could be reviewed at follow-up (Table 10).

Out of the 650 women eligible for cervical screening (75% of women), 515 (79%) had engaged which is a greater than observed across Yorkshire (76%, PHE Cancer in Yorkshire and Humber 2016 report). Of the 135 women who hadn't engaged in cervical screening, 70 (52%) set a goal to take steps to complete this. Ten of the follow-up completions had set a cervical screening goal through WUTC, with seven of these since taking action (70%) including two having completed and one having made an appointment.

Out of the 342 women eligible for breast screening (38% of women), 85% had engaged which is much greater than observed across Yorkshire (72%, PHE Cancer in Yorkshire and Humber 2016 report). Of the 52 women who hadn't engaged in breast screening, 31 (60%) set a goal to take steps to complete this. Four of the follow-up completions had set a breast screening goal through WUTC, with two since taking action including one having completed.

Out of the 335 people eligible for bowel screening (30% of all men and 22% of all women), current engagement was similar for both women and men (~73%) which is far greater than observed across Yorkshire (60%, PHE Cancer in Yorkshire and Humber 2016 report). Of the 37 men and 50 women who hadn't engaged in bowel screening, just over half (19 men and 27 women) set a goal to take steps to complete this. Three of the follow-up completions had set a bowel screening goal through WUTC, with two since having completed.

Just over half of the 1,285 people asked were aware of chest screening, with slightly greater awareness among women (57% of women asked vs 52% of men asked). Of the 50 men and 84 women who met the eligibility to have a chest screen, 12 men (24% of these) and 19 women (23% of these) set a goal. Nine of the follow-up completions had set a chest screening goal through WUTC, with five since taking action including four having completed.

Table 10. Overview of eligibility and engagement with screening at baseline and follow-up

	Cervical	Breast	Bowel	Chest
<i>Baseline</i>				
Eligible (% of all participants)*	650 (75%)	342 (38%)	335 (25%)	134 (10%)
Not completed (% of eligible)	135 (21%)	52 (15%)	89 (27%)	N/A
Set a goal (% of not completed)	70 (52%)	31 (60%)	47 (53%)	31 (23%)
<i>Follow-up</i>				
Completed follow-up	10	4	3	9
Answered follow-up question	10	4	3	9
Taken positive action (%)†	7 (70%)	2 (50%)	2 (66%)	5 (55%)
Completed screening (%)†	2 (20%)	1 (10%)	2 (20%)	4 (40%)
Not taken action	3 (30%)	1 (10%)	1 (10%)	4 (40%)

* Of all women for cervical and breast screening data

† % of those answering the follow-up question

4.4.1 Barriers to engaging with screening

Barriers to setting screening goals were noted by Barca as they arose during delivery – for cervical screening, six females were ineligible due to hysterectomy and two were unwilling due to a history of abuse and one participant stated they always threw away bowel screening kits as they do not want to complete. Furthermore, this participant also stated they would not speak to their GP if they were experiencing any signs or symptoms.

At follow-up, eight people had experienced barriers that had prevented them from taking steps to complete their screening goals including a lack of time and difficulty in obtaining a convenient appointment. One woman had not yet taken steps to get a cervical screening and an x-ray because at the moment she feels fine and another would like to lose weight before arranging to complete her cervical screening as she feels too embarrassed at *‘The thought of having an intimate examination.’* A third woman noted that she lacks assistance, namely the support and transport she would need to get to an appointment.

4.4.2 Summary

In summary participants already showed good engagement in screening, with rates higher than typically observed for Yorkshire. However, WUTC still identified over 400 incidences of missed screening opportunities (135 cervical, 52 breast, 89 bowel, 134 chest). A total of 179 screening goals were set – this tended to be about half of those who were eligible but had not completed, except for chest screening where the goal-setting rate was lower (23%). At follow up 6-8 weeks later, positive steps had been taken; out of the 26 screening goals which could be reviewed, 16 (62%) had made progress and 9 screens had been completed (35%).

4.5 Perceived learning from WUTC

111 of the 168 follow-up participants (66%) felt they’d learnt something through taking part in WUTC. In their reflections respondents focused on 3 main areas:

- Knowledge gained, including knowledge about healthy lifestyles, and monitoring your health, including the signs and symptoms to look out for.
- Motivation and reassurance.
- Advice received about consulting the GP/seeking medical advice, and arranging screening.

Knowledge

WUTC both provided new knowledge for participants plus acted as a timely reminder of information they may know but have not acted on: *‘It’s given me a wake-up call and made me more aware of the things I need to do and changes I need to make and a better understanding of why these changes can really benefit and help me.’*

Participants appreciated the information they gained and valued the importance of knowledge in taking responsibility for one’s health: *‘I think it is very important to know all you can about Wise Up To Cancer. I lost my dad in ‘84 to lung cancer but I think that things have progressed a lot since then.’* Participants on the whole acknowledged the relationship between lifestyle and cancer: *‘Look after your body to help the prevention of cancers.’* and *‘Sometimes our genes and age can have a part in the risk we run of getting cancer, but trying to live a healthy lifestyle can lower some risks.’*

Some participants had taken the lifestyle advice on board in a holistic way and felt that they are now more aware of the need: *‘To look after myself. To do more exercises, eat healthy foods.’; ‘Diet not only affects fitness but also general health.’* and *‘Good food (freshly made) using stairs, cycling to and from the library.’* Other comments focused on specific guidelines received: *‘Less red and processed meat is better.’; ‘The importance of a diet rich in grains, pulses and vegetables.’* and

‘Awareness of sugar in food and drinks. Extra salt and sugar on food.’ One woman related how she has applied the dietary advice to her children’s diet: ‘I feed my boys so we all need to eat healthier.’

Some participants had learnt where and how to access advice and support to make lifestyle changes: one person realised that *‘Help [is] available for stopping smoking.’*; whilst another can now identify *‘How to get help with losing weight.’*

Awareness of signs and symptoms had increased in some: *‘Increased my knowledge and awareness of potential signs to look for and consider.’*; *‘More symptoms to look out for with cancer than I thought.’* and the importance of knowing the early warning signs of cancer and of monitoring oneself and being attentive to body changes was identified: *‘Be aware of early warning signs and do something about [it].’* and *‘To look out for my skin [for] brown marks and how they change.’*

Others believe that they were already well-informed prior to the project and didn’t learn anything but nevertheless felt *‘It was useful to be reminded of a few things.’*; *‘It’s all common sense - just needed to be reminded every now and then.’* and *‘[I learnt] not a lot, as I had heard most of it before.’*

Some participants had learnt more about the regional context *‘[I learned more about] the good work carried out by Yorkshire Cancer [Research].’* and *‘[I learned] about Yorkshire not getting as much help towards the trust than London who receive more funding help from cancer research.’*

Motivation and reassurance

WUTC had increased motivation to make lifestyle changes and acted as a reminder for those who were already trying to make changes: *‘It is A LOT easier to make changes than you think. Little smaller changes over time will mean I reach my goal of becoming healthier.’*; *‘Small changes make a difference.’*; *‘I already felt like I was living a relatively healthy lifestyle but this certainly helped me continue to be motivated to work out*

more and eat healthier.’ and *‘This email has reminded me to pursue my alternative lifestyle.’*

Medical advice and screening

Learning about the importance of screenings and of getting signs and symptoms checked out was highlighted: *‘I have learnt that everyone should talk to someone if there have been any changes in or with our bodies. [Be] aware to discuss any changes small or big.’*; *‘Don’t just leave it get checked out.’*

The project had increased confidence when it comes to seeking medical advice: *‘I learned not to be afraid to contact my doctor if I feel it to be necessary.’* and *‘[I would] go back to GP or nurse prescriber if I ever have persistent symptoms that don’t change after first diagnosis and treatment tried over a period of time.’*

Some participants had learnt how to go about arranging screenings and where they are available: *‘I can obtain a chest x-ray at walk in clinics.’* and *‘Some screening ends at 70+ so it is good to know that it can be requested at a later age if needed (I am 74 but still have breast cancer screening as my mum had cancer at 80).’* For one person, being better informed as a result of the WUTC project means that she has *‘Better awareness of checking for breast cancer and the procedures involved when having a mammogram - coincidentally my appointment came through a week later so I was much better informed when it did.’*

In summary, it is evident, that the majority of respondents believe that they have learnt valuable things from WUTC, and feel more informed and motivated with regard to adopting a healthy lifestyle, monitoring their health and in seeking medical advice and screening. The general enthusiasm reported is demonstrated by one participant keen to share her newly acquired knowledge: *‘I teach exercise sessions and since taking part I have spoken to the class participants and asked them to look at why you have to “wise up to cancer” and make lifestyle changes.’*

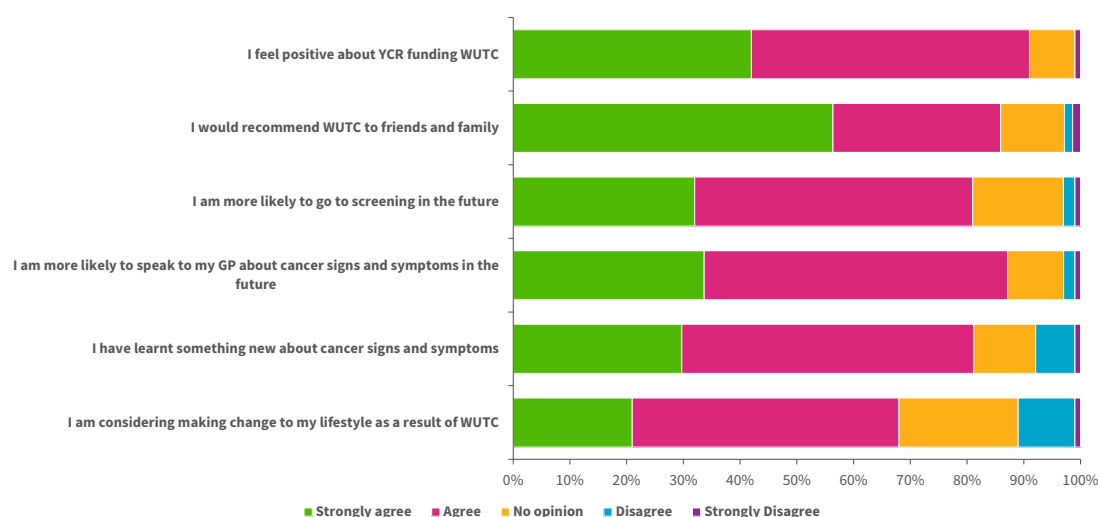


Figure 8. Responses to feedback questions at the end of the baseline questionnaire

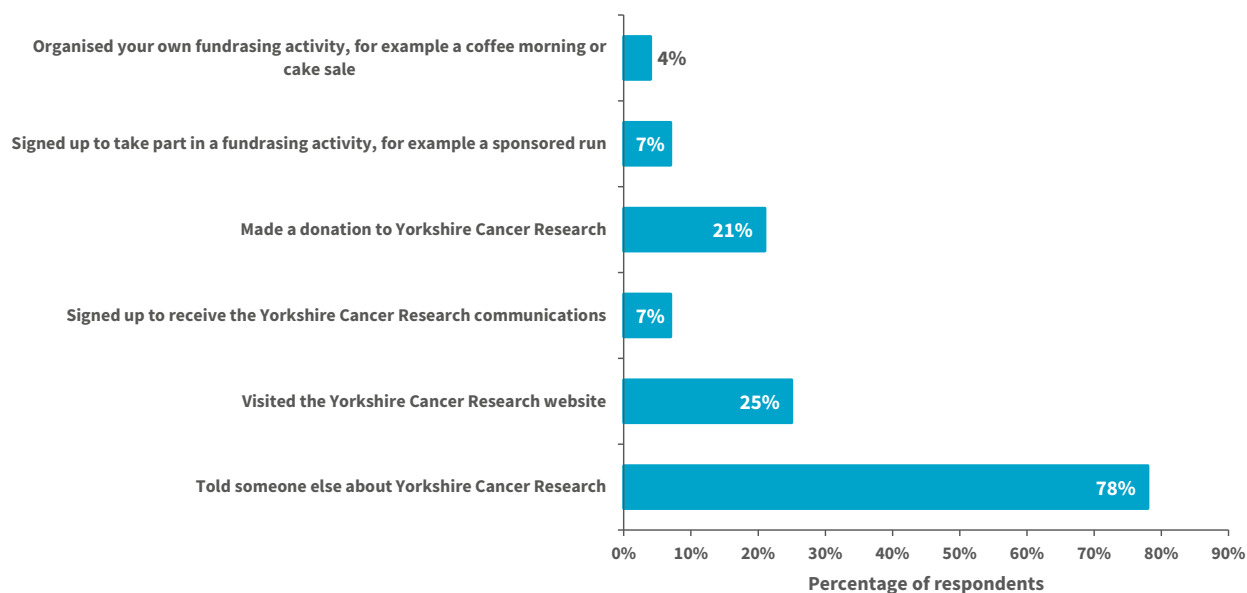


Figure 9. Action taken in relation to Yorkshire Cancer Research following WUTC

4.6 Intervention feedback

Baseline

520 people (40%) had not heard of Yorkshire Cancer Research before WUTC.

Of all WUTC participants, 91% agreed that they would recommend it to their friends and family and 91% felt positive about Yorkshire Cancer Research funding the initiative (Figure 8).

68% of people agreed they were considering making changes to their lifestyle as a result of WUTC, which is similar to the proportion of participants who set a lifestyle-related goal (70%). Those who disagreed may have felt they did not need to make any changes as some people were already following healthy lifestyle behaviours.

Over 80% of all participants agreed that they had learnt something new about cancer signs and symptoms and 88% agreed they were more likely to speak to their GP about cancer signs and symptoms in the future.

Follow-up

Engagement with and promotion of Yorkshire Cancer Research

109 of the 168 follow-up participants (65%) responded to the question relating to promotion of and engagement with Yorkshire Cancer Research following WUTC. Of those 109, 85 participants (78%) had told someone about Yorkshire Cancer Research, 27 (25%) had visited the website and 23 (21%) had made a donation (Figure 9).

Topics covered

96% of follow-up respondents rated this as 'good' or 'very good'. Respondents found the topics informative, helpful and interesting; *'It covered many areas and was informative.'* The variety of information covered was appreciated; *'Good topics for all ages.'*; and another that *'It was really helpful and I have made changes in my*

immediate family's lives.'

Some respondents commented favourably on the conversational format, saying it was *'Good that you can ask questions and see what's out there.'* Another person felt that the face-to-face aspect was beneficial, noting that *'It is nice to see people about these sort of things - it clears your mind.'*

Some participants had reservations about specific aspects of the information they received: one individual, for example, remarked on the difficulty of getting a doctor's appointment, something not covered in the project; whilst another felt *'The advice about increasing fruit in your diet is counterproductive for someone with diabetes. I find even a piece of fruit can cause my blood sugar to spike.'* Another participant, whilst acknowledging the need for 'generic' information, suggested that Yorkshire Cancer Research also *'Please look into adding some of the rarer cancers & signs/symptoms into your surveys/questionnaires to bring up awareness levels of these to the public.'*

Advice and support given

88% of follow-up respondents rated this as 'good' or 'very good'. The general view among respondents was that the advice and support were excellent/good, helpful, clear and informative *'The support given was very useful and inspiring.'*

Some comments focused on specific elements of the project; for example, one person identified the *'Very well presented'* health and wellbeing session; whilst another singled out the *'Helpful advice about mammogram screening.'*

The main reservation mentioned with regard to the support and advice given related to the degree of detail provided. One respondent was not quite satisfied with the amount of information in relation to recommended lifestyle changes, remarking that they

'Maybe expected some kind of more in-depth questions about diet and health and exercise.' and suggesting that the intervention *'Could have included a report with recommendations.'* One individual made a case for some form of follow-up/extension of the intervention, suggesting that *'Email prompts to visit the website would encourage me to visit it.'*

Not being able to follow-up on the advice given was mentioned, *'As Leeds City Council [is] in process of transferring [the weight management service] to a private company from NHS, a wrong move in my opinion.'*

Leaflets provided

88% of follow-up respondents rated this as 'good' or 'very good'. Participants thought the leaflets were useful and provided a variety of information that complemented the conversation/sessions with WUTC facilitators *'The leaflets that were given were helpful as I was able to see things from a greater perspective.'* Other respondents liked that they could select leaflets that were relevant to them: *'I took leaflets necessary for me but there was plenty of choice.'* with another individual valuing the leaflets as a way of sharing information: *'If you don't need them and to show to others.'*

There were very few negative comments regarding the leaflets, however, one individual felt that the facilitators could have explained them, remarking that *'Practitioners in attendance could have talked us through them.'* One commentator proposed an alternative version of the "Signs of cancer" leaflet, suggesting *'Something really simple that you can put on your fridge and maybe with a contact number or website if you have any concerns.'*

Length of time taken

86% of follow-up respondents rated this as 'good' or 'very good'. Participants remarked that it *'Didn't feel rushed.'* and *'Seemed to take as long as I needed.'*; and that filling out the questionnaire in the pharmacy *'Didn't take long.'* One respondent appreciated that there was *'Plenty of time to ask any questions I needed to.'*; whilst another noted that further help was available if required, that *'They will speak to you at any time.'*

Venue

87% of follow-up respondents rated this as 'good' or 'very good'. Whilst most participants found the venue satisfactory, some voiced concerns regarding the suitability of venues (e.g. being cramped or lacking privacy). There were some contrasting views with regard to provision for families: whilst one parent appreciated the consideration given to children accompanying parents, explaining that *'My daughter was playing dress up while I answered questions.'*; another was not quite satisfied and felt *'[It] would be good to have a venue [suitable] for families.'* Other issues mentioned included noise and other distractions: *'It was very noisy with a lot going on around.'*; and inclement weather at outdoor venues: *'It was raining,*

windy and cold in the park which made talking quite difficult.'

General intervention feedback

Many commented positively about the project and stated how useful and informative it has been for them. Others highlighted the friendliness of the volunteers/facilitators, and the conversational format which meant that their specific questions were addressed. Overall participants remarked on their appreciation of the project, which some found inspirational. One person revealed that *'As many of my family have lost their lives to cancer, I have decided to do a family run challenge for Yorkshire Cancer Research.'* A sample of other positive comments include:

- *'A great campaign that can have a positive impact.'*
- *'The women I dealt with were very friendly and put me at ease, which is extremely helpful when discussing such topics.'*
- *'The information is very helpful and if we can get the message out there it will help more people to learn and understand that prevention is key!'*
- *'Would recommend it to others!'*
- *'Good information that did not take long and could save lives.'*

Respondents also used this section to make a variety of suggestions about the project. Two people remarked that it would be beneficial to involve GPs more in the project: *'Get doctors involved.'* was one suggestion; whilst the second proposed that GPs might also benefit from more information/ training: *'More GPs need to be aware of the symptoms of cancer.'* One participant called for additional WUTC sessions in their neighbourhood, with the appeal: *'Please do more in Bramley.'*

5. Interview and focus group findings

5.1 Feedback from the people who had received the WUTC intervention

Opinions of WUTC

All were positive about WUTC. Trying to get people to be more aware of what they can do to tackle or prevent cancer was appreciated. It was felt that people are often scared of cancer so don't want to think about it – WUTC helps them address this.

'I think it's a brilliant title. Because, as you say, it's about being aware. And it can strike any age, and think that the trouble is that people would prefer to sort of keep their head in a bucket of sand or something like that than face reality if it's frightening. But if you don't face it early enough, it's too late to do anything about it.' (SU1-C)

The fact it was tailored to them, rather than just general advice was appreciated:

'It just gave me that bit of extra information that I needed. It wasn't the kind of information that World Cancer Research were actually giving me. Because they're just doing generalised information, this was more geared towards me.' (SU8-C)

People felt comfortable taking part and not rushed.

Reasons for taking part

Having a family member or a friend who had had cancer was the main motivation to take part. All were aware cancer could affect them and wanted to improve their knowledge. Some were actively looking to make changes to improve their health. Wanting to help Yorkshire Cancer Research and knowing the Pharmacy Champion also emerged as a reason for taking part.

'Erm, mainly because a lot of my friends have had cancer as well, so erm, my wife has still got cancer, so I thought I would try and sort of look after myself as well, and try and not get cancer and if I do, what's the best way to tackle these things 'cause it is becoming more, more common unfortunately. Just to find out information really. Yeah, and how to go about the, any recommendations as well, early signs, that sort of thing as well.' (SU5-C)

'I think one of the things were, a family friend has just recently been diagnosed with cancer, and I just wanted to kind of see if there was anything, you know, that I could keep in my mind to think of, you know, just signs to watch out for, I guess.' (SU4-C)

The setting

The convenience of taking part was key. No one had actively sought to participate but had seen it in their local shopping centre, at a festival or it was mentioned to them in a pharmacy. Conducting WUTC in the community/pharmacy was seen as important as people are more relaxed meaning they open up more - many are intimidated by going to talk to a GP about cancer.

'So I think the fact that we were approached when we were like obviously during our leisure time at the weekend, taken by surprise and obviously benefits could come out of that. So I think that's a good plan 'cause people are too scared.' (SU11-C)

'Because you know people are scared of doctors, people are scared of the "C word" anyway. So by people coming to you and going round places it's like you know even if they don't, people listen, don't they?' (SU6-C)

The approach

The intervention itself was praised. The friendly, helpful approach of the CHEs and Pharmacy Champions and their personal insight was appreciated by all the participants. One emphasised how they didn't preach, which normally put them off. They were seen as well informed and knowledgeable. Only one participant mentioned the interaction feeling a little scripted.

'She were really nice 'cause she were right friendly and forthcoming and she sort of like explained everything to you so you were at ease and you knew that if you were to ask, ask a question that you would, she would be alright to answer it, you know, she weren't. Like basically, I think, she were quite a nice warm person so it were quite easy to talk to her. ... It were quite good 'cause she actually put a bit of personal insight into it as well, which were nice.' (SU3-C)

'Oh yeah it weren't rushed, she was lovely. She explained everything in detail. Yeah and she also talked about people that she knew, you know in relation to the questions she was asking. So yeah, it was quite good actually yeah. She was lovely the lady.' (SU13-P)

Privacy was important, with all participants mentioning the need for a quiet place to talk so they felt comfortable. One participant at a festival had felt privacy was not optimal.

'It was in the confines of like a sort of SUV and it was quite safe and quiet, and I don't think there was no-one, you know, other people weren't, there were no-one to like, overhear what was said, where you could give quite confidential information, quite sensitive information.' (SU2-C)

Resources

Nearly everybody was positive about the leaflets that had been developed for WUTC, saying they contained enough, but not too much information. They were seen as clear, in plain English and having a good format. Only being given relevant leaflets was important.

'I think it were the formatting as well, and layout, and there was all the colourful pictures, very attractive. But the information on the leaflets were quite, I don't think they were exhaustive to read. I felt it was quite nourishing, it was quite interesting information, it were

more persuasive as well.’ (SU2-C)

‘And she only gave me leaflets that were appropriate to me. She had a whole host of them, but she did select the ones that she felt were appropriate to me. [When given too much information] you think “What the hell? There’s nought to do with me.” So you throw them all to one side. But because I actually saw her selecting them I realised that she was doing it geared towards my circumstances, so I paid more attention to them.’ (SU8-C)

The laminates used in pharmacies to explain alcohol units for example were helpful too.

Knowledge and awareness

People said WUTC helped act as a ‘wake-up’ call – whilst everyone is aware of cancer, people often put it to the back of their mind.

‘[I] just think it, it just opens your mind and gives you like, I don’t know, just a bit of information being given just then makes you think about it a little bit more. Whereas I think, it just, I don’t know, it just switches something on I guess, to think “Hang on a minute, I need to research this more” or look into this whereas without, I know for a fact ‘cause if I hadn’t had that meeting with [the CHE] I wouldn’t have checked on my smear.’ (SU4-C)

The amount of knowledge gained varied. Some felt they had already known a lot of the information but others felt WUTC had resulted in them being more informed.

‘It’s quite opened my eyes to certain things that you weren’t actually aware of that can trigger things off.’ (SU3-C)

Others had gained specific knowledge about screening or diet – some mentioned passing this new information onto friends and family members. One man, with a persistent cough, said:

‘What I didn’t realise, when you reach a certain age you can actually go and get an x-ray done, well not straight away but you’re able to get one anyway without an appointment.’ (SU5-C)

‘I’ll be more aware of what the signs and symptoms are for bowel cancer, so for the, I would definitely go to the doctor or the local GP especially if it were me or family members or anything like that. And to be more aware of what I’m eating as well, and how like quite a lot of fibre really helps me, maintains good health and my bowels, so yeah I would be more aware of that. I feel the information that’s been provided was very invaluable to me.’ (SU2-C)

Lifestyle change

Many of the people we spoke to had made a lifestyle change that they attributed at least in part to WUTC. These ranged from major changes such as giving up smoking (two people) to changing their diet (e.g. reducing consumption of red meat or joining Slimmer’s World), reducing drinking (limiting it to weekends), joining a gym or starting to walk more. One participant

had lost 17lb after joining Slimmer’s World.

The two smokers who gave up had both been wanting to or thinking about changing (one had a partner who’d died of lung cancer, another had heart disease) but WUTC encouraged them to take that step. One talked about now feeling much healthier and more able to breathe. The other had forwarded on the information to his step-brother, who has also given up smoking.

‘Yeah, after I’d spoken to her and I confessed that I’d started smoking again, and we talked about it. We were talking about all the carcinogenic and all the dangers of it. And I just thought, “She’s right.” I mean I came out of there and they were in my pocket, I crushed the cigarette packet, threw it in the bin, and I haven’t touched them since.’ (SU8-C)

Those who had not made a change often said they were already leading fairly healthy lives. Others were struggling with a disability or motivation due to being stressed and worn out from work.

Interaction with healthcare

Most participants had not changed their behaviour as regards screening (most seemed to be aware of their eligibility). A few had checked when they were due, with the intention of going. One male participant had not gone to breast screening, despite being advised to by a GP, as he was embarrassed to attend a female orientated clinic. Another, who had a persistent cough, was not intending to go as he was convinced it was a minor issue.

A couple of participants had gone to their GPs to check out signs and symptoms. One booked an appointment with her GP immediately after receiving information from a Pharmacy Champion – she had subsequently had a biopsy on her moles that was all clear.

Improvements

People who had received the intervention suggested two areas for improvement:

- To reach out to more people including younger, currently healthy people so they could improve their lifestyles before it was too late. Talking to mums at schools or going to sporting events was suggested, as was focusing on poorer areas.
- Raising awareness of the initiative and Yorkshire Cancer Research.

5.2 Feedback from the Pharmacy Champions

Opinions of WUTC

All the Pharmacy Champions were very positive about WUTC and thought the focus on prevention and early detection was critical. Their customers were receptive and nearly always found out something new. The fact WUTC was Yorkshire based was liked, as it felt it was ‘for them’. A key motivator was that everyone had been ‘touched by cancer’ and therefore the more knowledge the better.

'Well I think it's a no-brainer; I think it's absolutely fantastic. Anything to make people aware isn't it? And especially being in the community you know, and making people locally involved with the research, it's fantastic.'

Universally the Pharmacy Champions felt pharmacies were an ideal place for WUTC to be delivered. This is because of their core purpose of improving health and wellbeing, knowledge of local services, relationships with local people, accessibility/position in the community, and that people could return if they had any questions. Healthy Living Pharmacies were felt to be a particularly good fit.

'And I think a pharmacy is a good place because that's what it's all about; health and care and wellbeing. So it's not alien. So to speak about an illness within a pharmacy cos that's exactly what we're about.'

The format of WUTC in pharmacies (a paper version of the questionnaire, later inputted into PharmOutcomes) was good – it gave structure but allowed some flexibility – though a couple mentioned the length being off-putting. Some people did not want to be weighed whilst a couple of Pharmacy Champions felt some questions were too personal or intimate.

The leaflets were seen as colourful, well-designed and containing useful information. Some Pharmacy Champions however felt leaflets generally are over-used so people don't always pay attention to them. The laminates used by Pharmacy Champions to explain, for example, alcohol units, were helpful though some suggested combining them into the questionnaire so they did not get lost.

Reaching people

Most members of the public were very receptive to WUTC. This is particularly true of older people who had more time. Knowing their customers also helped. Many said the most difficult group of people to engage with were men, particularly middle-aged ones. It was felt they did not want to talk about health and tended to be more task-focused e.g. picking up a prescription.

'Men don't have time; they don't want to divulge. I think females are much easier to talk to; they want to tell you their whole life history. We've had the odd older gentlemen and I mean old and they're happy [to engage]. Maybe it's because they're lonely I don't know. But if you are talking to a smoker and he's like thirty, he's not probably gonna wanna sit and talk to you about stuff like that. So I think they are a little bit harder the males.'

Success factors in reaching men included having a male Pharmacy Champion and holding events.

Approaching people needed to be done 'with care' in a relaxed and private way, appreciating when it may not be appropriate.

'We thought, let's do a gentle approach. And I must admit from then on it's been phenomenal. Because they liked

that gentle approach that you're not talking in front of other people, you just go in and have a little chat. And everybody, I would say everybody has taken part in the questionnaire now we've done that.'

Tactics that worked included tying in with the flu-jab or whilst people were waiting for their prescription. Tea parties were a good way of increasing numbers as was saying to people they were 'Helping Yorkshire Cancer Research with their research.' The scratch-cards were not liked by some as it was felt they trivialised the issue and were too strong an approach.

Barriers to people engaging included being in a rush, having children with them or not fully understanding the project.

Having been affected by cancer acted as a barrier for some, but conversely often acted as a motivator to taking part. This could lead to long conversations about their experiences which the Pharmacy Champions wanted to be sensitive and understanding about but are aware they need to continue with their work.

'I've got to give every ounce of me to that person. Because when they're telling you something it could be something quite devastating within their life. So you can't, it's something that you can't rush through basically. It's a big responsibility.'

Finally, some Pharmacy Champions felt that the criteria were too narrow and it should be broadened to include any adults. The rationale for this was anyone can be affected by cancer and increased knowledge is an important outcome in itself.

The Pharmacy Champions

The most important skills and qualities for a Pharmacy Champion were seen as confidence (both in approaching people and in their own knowledge) and people skills – being able to make people feel comfortable, to listen to them, to understand and be compassionate, whilst also keeping them 'on track'.

'I think you do need to have the confidence to be able to talk about it with people, because it's quite a hard one to approach people with or I thought it was.'

'I think you need to be a good listener. I think you need to be articulate. And I think you need the training and be confident in what you're talking about. Any questions that they have, research them beforehand so you can answer them. Be understanding really. So yeah, you've got to have them qualities and you've got to be a people person I think.'

The training and support provided by CPWY was universally praised. Having a person on hand who could answer their questions and give them extra motivation or support (for example at an event) was critical. Some emphasised the need to practise approaching people and delivering WUTC so they could perfect their phrases.

'She's [the CPWY Manager] regularly phoned us and given us updates so we know, and [asked] if we need any support. And she's come in on Wednesday as well to give us some more ideas and to try and help. So the support has been there definitely. We've not felt like we've been on our own with it, and if we've needed any help or just a bit of support, then she's been there.'

Barriers to hitting the targets (additional to those above) tended to involve the difficulty in finding time in a busy pharmacy to deliver the initiative. Increased foot-fall meant more people to approach but staff would also then be busier – some may be stuck 'out-back' and weren't able to devote the time for the intervention. Lacking staff or staff changes exacerbated this, as did only having one consultation room.

'To take someone out to sit for a while with a customer in the consultation area is sometimes hard, a busy process. But at the same time it's like a vicious circle cos when you're busy that's when the people are in to sort of approach about the scheme. But when it's quiet obviously that's the time when you have the time to do it. But the other thing we've found was when our own services kicked in like flu and medication reviews we only have one consultation area. So that was like you know priority who gets the use of the consultation room.'

Having more than one member of staff trained was helpful.

Follow-up

The main barrier to recruiting people to the follow up was that people were unsure or wary about what the information would be used for. People were worried they'd be asked for money or be inundated with information. It could also feel like they are being checked up on. Some older people did not have email accounts. Being clear about what the information would be used for (the limits) is critical for gaining people's trust.

Impact

Four key potential areas of impact were explored, as below:

Signs and symptoms

This, the Pharmacy Champions felt, was where impact was felt most strongly, with most people learning something new. Whilst the obvious signs and symptoms were known, less obvious ones were not.

Behaviour change

Getting people to set a behaviour change goal was difficult. Pharmacy Champions emphasised making small, achievable steps, however, often people did not want to commit to a change, were actively not wanting to alter their lifestyle or were stuck in certain habits. Sometimes, all the Pharmacy Champions could do was 'plant a seed'.

'I'll just reassure them again, and I'll say you know you can only do what you can do, and start from today. And

you know there's little things you can change. I'll say just make that one change. Don't juggle lots of different changes in your mind. Don't struggle with that, just make that one change and just work off that, and the rest will follow.'

Screening

Only small numbers of people had not attended the screening they should. One example of a woman who had not attended her cervical screening – but now would – was given. Another example was given of two men who had not attended their bowel screening, but refused to consider it.

Signposting

The Pharmacy Champions felt in touch with the local signposting opportunities available. Smoking and weight management were the most common with physical activity opportunities also communicated. Signposting to drug and alcohol services was less common as these were more sensitive issues.

Improvements

Pharmacy Champions were, in the main, very positive about WUTC, so suggestions for improvements were limited. These include:

- Having more staff in each pharmacy trained.
- Widening the criteria so all age groups were approached.
- Greater awareness of Yorkshire Cancer Research generally locally.
- Hand-out format – something people will keep (e.g. a fridge magnet) as opposed to a leaflet.
- Explanations of units/what red meat is/healthy plates – as handouts.

5.3 Feedback from the Community Health Educators (CHEs) delivering the initiative

Opinions of WUTC

The CHEs were all very positive about WUTC. They felt it was an important issue to tackle in Yorkshire and welcomed the emphasis on prevention;

'Yes, I think it's really good that you're carrying this out. And if this helps to help people understand about making dietary life changes, and taking more exercise and eating and drinking less, and smoking less, then why not. And I just feel that it [cancer] feels like an epidemic in Yorkshire.'

The fact it was personalised to people was important.

Reach

The CHEs feedback is that people, from across different cultures and socio-economic backgrounds, were receptive to WUTC and keen to take part;

'The feedback we've got [from participants] is really good. People are taking part, people are coming to us, they are choosing to come.'

'Just a few people they will say "Oh I don't have time" and all that. But apart from that, everyone, if they have

a little time, they are able to participate. And especially with the market area, they have all categories of people, ethnic minorities and indigenous and all that; and you find equal [participation].'

The CHEs felt they were able to reach men as well as women, often approaching them at festivals when they were part of a couple or whilst at work. Some men, they thought, preferred being approached by another man, but others did not have a preference;

'I think that some of them [men] would like their same gender to help them do them. Just quite a few of them, and some of them, they don't care whether it's a man or a woman who interviews them.'

Of interest is that one of the CHEs participating was an Asian woman. She had worked closely with an Asian women's group to deliver WUTC.

Format

The CHEs liked the questionnaire and going through it with people on the tablets was generally working well. Having a structure helped ensure they did not forget things and the filtering of the questions depending on gender/age was helpful. The only issues mentioned were a malfunctioning tablet and perceived duplication of questions (regarding goals and having to input email addresses twice).

Approach

The key qualities for CHEs to have are being good listeners, effective communicators and to have empathy. They needed to be approachable, able to relate to people and be able to explain WUTC in an understandable way. Some used facts about how making changes to their lifestyle could reduce their risk of cancer.

'You need to make people feel comfortable to relate to people really well, making them comfortable and them trusting you [are important qualities].'

The CHEs agreed that often people found it easier to talk to them than to health professionals;

'They've had experiences with doctors, of telling them what they should be doing in a certain way and that makes them like close up really, whereas for us, they feel like they can talk to us and open up to us and that enables us to help them to make changes.'

The initial training plus top-ups (generally relating to the questionnaire) were important so they felt confident in what they were doing.

Using the words 'health-check' led to confusion with people often saying they had already done one health-check at the Doctors. The CHEs then had to explain the difference;

'They say, "Oh, no, we've had a health check at the surgery and stuff." And I say "Well, this is completely different. It's just a simple questionnaire that asks you

about your lifestyle factors and making you aware. And it's in conjunction with Yorkshire Cancer Research, Leeds Beckett'"

Settings

CHEs talked positively about delivering at festivals, in markets, at shows and community fairs. Libraries had initially worked well but more recently numbers had dropped – it was felt people were there to do something particular and did not want to be disturbed.

The chosen setting affected the type of people the CHEs engaged with. Separate to the main project, CHEs delivered WUTC at the Great Yorkshire Show in Harrogate, this had raised the issue of health inequalities, emphasising the large differences in people's lifestyles depending on their affluence;

'There were very posh people there. Oh my God, discoveries and things. But they had very good lifestyles. And then when you compare it to maybe Leeds [LS]12, where people didn't have such good, posh lifestyles. They lack the money, leading to other problems like poverty and health, and they have been reduced to drinking and smoking, and they're not so good lifestyles. And I got sad, and I knew why then the Chair of this organisation is very passionate about removing isolation and poverty and I understood that there is a big gap.'

Barriers to participating/delivery issues

- People having children with them.
- Confusion over term 'health-check'.
- People's first language not being English.
- Lack of privacy.
- Too much noise/interruptions at some venues – too quiet at other venues (e.g. library).
- People not wanting to engage when approached in a public setting (e.g. a shopping centre) probably because they thought they were trying to sell them something.
- People focused on other tasks e.g. at a library.

Signs and symptoms

The CHEs felt many people knew some signs and symptoms but they were able to educate them about others (e.g. coughing).

Screening

Only a few people were open about not going to the screening they were eligible for;

'If you ask most of them, they say, "Oh, yes, I have been." Most of them. If they need to go, yes they have. It's just a handful of people who would say, even though the letters come, but they don't. So you kind of encourage them to do that.'

Negative attitudes towards screening did however exist, even amongst the family members of CHEs;

'It's just making people aware of it, you know, going for the screening. Like my daughter yesterday said, "Oh, I've got this letter from the hospital. I've got to go for this

screening.” I was like “You must go, you must go.” That’s what I do, I said, “Go and get your screening.” She said “I threw it in the bin, Mum”.

Lifestyle changes

The CHEs felt that many people wished to make changes but they perhaps lack the ability or the help they need to do this. This is particularly true of weight or diet related issues. They felt the role of the CHE was to encourage them, to signpost them to places that can help and to emphasise that they make changes gradually ‘bit by bit’;

‘In terms of the weight loss and the exercise, yes. Yes, you talk to a lot of people and they say, yes, they want to do something about it. But even though they want to do something about it, how to do it, the readiness to do it. They have the desire, their passion. So you just encourage them to go to other places where there is help that they could seek. And those who smoke, for instance, some of them might want to stop. But they’re not very sure how to do it.’

Smoking or drinking behaviour was more complex. Whilst some people did want to change, many did not; ‘They don’t want to stop because that’s their pleasure, that it’s not too much, it’s not excessive.’

Barriers to making changes:

- People not wanting to change – either because they were set in their ways or got pleasure from the risky behaviour (particularly drinking) and didn’t want to forgo that.
- Elderly people with painful joints etc. finding it difficult to be physically active.
- Several people mentioned not being able to get convenient and timely appointments with their GP.
- For those drinking too much alcohol (but who are not alcohol dependent) there isn’t a service to refer them too to help them to cut down.
- Lacking the money to buy fresh fruit and vegetables.

Improvements

The CHEs we spoke to had some ideas for improving the roll out of the initiative going forward;

- Spreading out the WUTC training a bit more – new CHEs in particular found it too much to take in, in one day – and providing refreshers, particularly for any CHEs where there was a gap in delivering the initiative.
- Allowing more time (30 rather than 15 minutes) for the intervention with some people e.g. elderly people, or those whose first language was not English.
- Rolling the initiative out to black and minority ethnic communities – need to ensure there are enough CHEs with appropriate languages and translate questionnaire and resources.
- Consider using more screens to create private spaces to do the assessment at public venues, and reducing the number of CHEs operating in the mobile library

van at any one time.

- Maybe resources ‘In larger print for some people’.

The CHEs we interviewed definitely thought WUTC should be rolled out further:

‘There are a lot of deprived areas in Yorkshire and I think there’s definitely scope for rolling it out in other areas, definitely, because it’s people that aren’t going to GPs as well and aren’t presenting.’

5.4 Pharmacy Manager feedback

Most of the feedback from the Pharmacy Manager concurs with that given by the Pharmacy Champions. This applies particularly to: the opinion of the intervention, reaching people (who and how), format and follow-up. Rather than repeat this, we will focus here on areas relating specifically to managing WUTC plus any areas of difference.

Engaging pharmacies

A key topic of conversation was how best to engage with pharmacies and support their WUTC activity.

Within each pharmacy at least two members of staff were trained as Pharmacy Champions to deliver the full intervention - though in some the whole team were included. All staff were able to refer eligible people to the Pharmacy Champions. The most active Pharmacy Champions were counter staff.

Being personable and able to engage with members of the public was identified as an important skill both by the manager and Pharmacy Champions. The Pharmacy Manager also identified being able to understand the project and being committed to WUTC. In some cases, whilst the Pharmacy Manager may have agreed to participating, buy in from individual members of staff may at times be lacking.

Barriers to delivery identified include; staff changes, a lack of staff time or a lack of focus due to other competing initiatives. Having a slightly shorter intervention could, it was felt, reduce some of these barriers.

What makes a pharmacy successful at WUTC was their relationship to the community and having a whole team involved;

‘It’s definitely a team approach, and it’s about the engagement from the team. And I think a little bit about how personable they are, how they approach, with you know what’s their relationship with their customers? But I do think it’s quite important that the team, and that they are a full team, rather than ... the struggles have been that they’re not fully staffed.’

A suggestion was made to ensure a proportion of the incentive reached the individuals delivering the intervention.

Training and support

Pharmacy Champions received an initial training session followed by regular support from the Pharmacy Manager often in person but also by email and telephone. This on-going support helped iron out any problems, sustain motivation and spread ideas. Communicating with the Pharmacy Champions was time-consuming as the pharmacies as a whole had an email address as opposed to the individual Pharmacy Champions.

A more interactive group training session that lets WUTC practise the intervention on each other was suggested as a key improvement. This would also include more information about Yorkshire Cancer Research.

Reaching people

The Pharmacy Manager agreed that reaching men was more difficult whilst older people were easier to engage with. Barriers included people being in a rush or having children with them. An additional barrier mentioned was some people not being appropriate for the intervention (e.g. those receiving methadone). How to reach the less healthy was a key consideration for the Pharmacy Manager as it was recognised that it is easier to reach those people who are actively trying to stay healthy. A potential link to workplaces was not possible to progress as the employers wanted WUTC to be done at their place of work. Instead leaflets were distributed to encourage people to go to the pharmacy.

The launch was a success with key partners including a councillor and the local rugby team mascots attending. How best to convert this interest into WUTC participation is an issue to consider.

5.5 Community Manager feedback

Again, much of what the Community Manager fed back concurs strongly with the CHEs. In this section we therefore only include topics that focus on management issues and any that differ from earlier feedback with pharmacies and support their WUTC activity.

Training

Much of the training (the knowledge about cancer screening, signs and symptoms plus key messages) was felt to be very positive. However, the Community Manager felt that, in hindsight, there needed to be more emphasis on the technology (using the tablets), how to input the questionnaire data correctly and, more broadly, the importance of the evaluation. CHEs are recruited for their skills in approaching and engaging with people (something that is difficult to teach) but may lack experience and confidence in using technology. Addressing this early on in the training process by, for example, more time practising on the tablets, could have reduced the amount of time correcting mistakes in the data once delivery was in progress.

‘Not everybody is a data person and a communicator. So it’s understandable that there have been errors. And I think it’s easier to teach data collection than to teach somebody to be a people person that can talk about sensitive topics. I think it’s definitely the right approach to get the community people and then train them.’

CHE profile

One aspect of reaching key target audiences that was discussed, was the profile of the CHEs. It was felt that there was an advantage in having a variety of CHEs in terms of ethnicity, age and gender as people from similar backgrounds or demographic profiles may open up more to each other and be able to relate better;

‘Taking [CHE name] who is a South Asian woman to a South Asian women’s group, the benefits of that are just unreal. Like she can talk about her own personal experience, but the fact she’s also from their culture makes it a lot more relatable. And they see “Oh, well she’s going to her breast screening appointment, I should go for mine.” And now we’ve got a couple of men on the team to talk to men about male symptoms they’re more likely to open up.’

Reaching men

The bias in favour of women that is evident in the figures, was felt to be partly due to men being less likely to go to community groups. At social events and festivals recruiting men to take part was easier – and whilst they could be initially resistant, once they engaged the conversations were often more detailed;

‘Men, once they’ve kind of got somebody’s attention they do sit and talk for quite a long time. So once we’ve got them, which is a bit more of a challenge they open up more than women sometimes, which is surprising, surprised me anyhow.’

Literacy/language

Two issues were raised here. When the service users do not speak English the initial intervention requires greater support than normal and takes longer – affecting the ability of the team to hit target numbers. In addition, those who cannot read/write English (either the illiterate, the visually impaired or those who do not speak English) cannot complete the follow up;

‘I would have liked to have done more work with different cultural groups. I think the health check’s quite White British focused. Because there is just so much, it’s a twenty-minute conversation, and if you don’t speak English you’re not going to be able to do that.’

Settings

Using a variety of settings to deliver is important. This ensures that different types of people are reached. Settings that had worked well so far included community groups and festivals. The former was an efficient way of reaching people as WUTC could be explained to everyone together. At festivals this needed to be done individually but the advantage was families,

men and younger age groups were more likely to be present.

The setting also affects how long the intervention takes. At a festival when people are wanting to move on, it tends to be shorter whereas at a community event where WUTC is the main focus it tends to take longer.

Links with workplaces and GP Practices were being actively pursued but had not yet resulted in any interventions. It was anticipated that these would target key groups of people – those not attending their screenings (in the GP Practice) and men (in the workplace).

Developing links with new community groups, workplaces or organisations takes time and perseverance. As such, using an organisation with existing links and networks is important.

The format

The lifestyle section could take a great deal of time to complete, whereas it was felt the biggest potential impact in reducing cancer related to communicating key signs and symptoms were and encouraging screening. It was therefore suggested that these sections be swapped round with the lifestyle questions last – this would mean that when people's attention was at their best (the beginning) the most important information would be being conveyed.

Logging if someone was illiterate on the questionnaire was suggested so they did not get sent an email follow up to complete.

Signposting

Part way through delivery the lifestyle service in Leeds that was being signposting to was recommissioned. This caused frustration as the support for people to change their behaviour was not available.

5.6 Summary

The interview and focus group data presented above comes from three groups; people who had received the WUTC initiative, those who had delivered it and those who had managed the initiative. Between these groups of people there was a great deal of consensus. WUTC is perceived positively by all the groups because of its emphasis on the prevention/early diagnosis of cancer, the fact that, whilst it is structured and provides useful information, it is tailored to individuals and its focus on Yorkshire. Key positive aspects of the approach are the personal skills of those delivering (their friendly, non-judgemental manner) and that it reaches people where they are (in community and in pharmacy) so they are more relaxed and open.

Some differences in regards to delivery emerged. In pharmacies the main issue was staff having the time, the focus and the space to deliver, as Pharmacy Champions had to absorb WUTC into their normal working day and with existing responsibilities. In the community (Barca) the most cited issue was how

to reach people who did not speak English, or were illiterate. In this setting they were able to adjust their activities more readily to reach different groups, but this did impact on target numbers. Training generally was perceived positively but in pharmacies it was felt the Pharmacy Champions needed more assistance in developing the confidence to approach people (maybe by practising delivering the intervention) whilst the CHEs needed more practise with managing the tables and inputting the data.

One slight difference between those delivering WUTC and those receiving it was that the former tended to emphasise the importance of taking 'small steps' and the difficulties people in making changes, whilst the latter had often made significant changes to their lifestyle. Whilst this is cause for optimism it must be remembered that those who agreed to be interviewed probably felt most positive about the initiative.

6. Yorkshire Cancer Research communications outputs

6.1 Wise Up To Cancer launches

The Barca Leeds launch of WUTC in February consisted of a Family Fun Day at Bramley Shopping Centre. This involved the WUTC questionnaire being delivered on the Leeds City Council's mobile bus and other health awareness and children's activities. Stakeholders including MP Rachel Reeves, other local councillors, Leeds Rhinos mascot and representatives from Yorkshire Cancer Research, Leeds Beckett University and Barca Leeds attended.

The pharmacy launch in May consisted of a gazebo outside Lloyds pharmacy in Castleford to increase awareness of the initiative and delivery of WUTC in pharmacy consultation rooms. Stakeholders including Councillor Richard Forster, Duncan Cooper (Consultant in Public Health at Wakefield Council), Castleford Tigers mascot and representatives from Yorkshire Cancer Research, CPWY and Lloyds pharmacy in Castleford attended.

6.2 Media activity

The following media coverage was received:

Barca Leeds launch:

- Yorkshire Evening Post
- Made in Leeds
- Leeds Beckett University School of Health and Community Studies Staff Newsletter
- Leeds Business Review.

Pharmacy launch:

- Wakefield Express and Castleford Express
- Ridings FM headline news story every hour between 9 and 6pm.

6.3 Website and social media activity

The following website and social media activity was received:

Table 11. Website page views

Webpage	Page views
Yorkshire Cancer Research WUTC webpage	442
Barca launch news story	146
Pharmacy launch news story	60
Wakefield Council webpage with link to WUTC webpage	183

6.4 Keeping in touch with Yorkshire Cancer Research

Once the WUTC questionnaire is completed, CHEs and Pharmacy Champions are encouraged to ask the individual if they consent to their contact details being recorded on a 'Keeping in Touch' form and passed on to Yorkshire Cancer Research to receive communications. CHEs and Pharmacy Champions are also encouraged to capture any potential patient stories for Yorkshire Cancer Research case studies.

85 people have signed up to the Yorkshire Cancer Research communications, all in Barca Leeds community settings.

CHEs and pharmacy staff have experienced barriers to achieving participant to keep in touch. These barriers include:

- Time – completing the questionnaire takes a sufficient amount of time and once this is completed, participants are keen to leave.
- Many participants are concerned about their contact details being shared for marketing and communications purposes.

Table 12. Yorkshire Cancer Research social media activity

Social media post	Facebook	Twitter
Barca Leeds launch (17th Feb)	2,055 people reached 43 engagements 2.09% engagement rate	12,005 people reached 180 engagements 1.5% engagement rate
Pharmacy launch (11th May)	904 people reached 16 engagements 1.77% engagement rate	8,917 people reached 121 engagements 1.35% engagement rate
General WUTC post	1,279 people reached 14 engagements 1.09% engagement rate	1,164 people reached 15 engagements 1.3% engagement rate
Barca Armley Breeze Leeds event	1,374 people reached 6 engagements 0.43% engagement rate	1,018 people reached 17 engagements 1.7% engagement rate
Barca Lord Mayor Leeds Wise Up To Cancer	704 people reached 2 engagements 0.28% engagement rate	1,085 people reached 19 engagements 1.8% engagement rate

7. Summary and recommendations

7.1 Summary

WUTC targeted people living in deprived communities and primarily aimed to decrease behaviours associated with cancer risk, increase awareness of signs and symptoms, increase participation in screening programmes and increase signposting to relevant services. The initiative also had a secondary aim to increase awareness of Yorkshire Cancer Research.

This evaluation, nine months after delivery started, shows WUTC has been successful in targeting those at greater risk of developing cancer. Overall, participants were more likely to be overweight compared to the general Leeds and Wakefield populations and pharmacy participants were more likely to smoke than the general Wakefield population. 1,347 people in the community of West Leeds or in a Wakefield pharmacy having taken part in an in-depth, personalised conversation about cancer with a Pharmacy Champion or a Community Health Educator. Whilst this has not been directly assessed, it is anticipated that this could contribute to Yorkshire Cancer Research's goal of reducing cancer deaths in Yorkshire by 2,000 per year.

Establishing this novel initiative has been challenging at times, but, as this report shows, there is much cause for optimism. Data captured at the baseline assessment and at the follow-up six weeks later demonstrates many positive results. In addition, qualitative feedback shows that members of the public, many from deprived communities or living 'unhealthy' lives, are very receptive to WUTC. Often motivated to take part by friends' or family's experience of cancer, they welcome the opportunity to learn more about how to prevent the condition, and are willing to make commitments to change key behaviours. The approach was almost universally praised, in particular the friendly, approachable manner of those delivering, the structured format and the useful personalised content. Both settings piloted yielded positive results – being in 'the community' and outside of primary healthcare was important.

It is important however to remember that there may be a bias in the data towards positive action, with those who were able to make changes and/or achieve their intended goals being more likely to complete the follow-up questionnaire.

We recommend rolling out this important initiative to other similar deprived communities to ensure those living unhealthy lives are targeted (particularly men) and on how to ensure a follow up, now the evaluation has ceased. In addition, we recommend piloting how best to deliver the intervention in communities that have had less engagement so far, yet carry an increased cancer burden – for example, BAME communities who may not speak English as a first language.

7.2 Meeting the aims

Primary aims

WUTC aimed to decrease behaviours associated with cancer risk

948 participants (70%) set at least one lifestyle-related goal – most commonly around losing weight/improving their diet (704 people), increasing physical activity (418), reducing alcohol intake (93) or reducing tobacco use (166). All of these actions can positively impact on cancer risk. Those people most needing to change were indeed setting goals:

- 424 overweight or obese people (66%) had set a goal to reduce their weight and/or eat a healthier diet.
- 381 inactive people (47%) set a goal to be more active.
- 93 people who consumed alcohol (10% of alcohol consumers) set a goal to reduce or cease alcohol use.
- 166 people who smoked (49%) set a goal to reduce or cease tobacco use.

Most people who could be followed up had made positive steps to change. The percentage of those who completed follow-up, had set a goal and made 'some progress' 6-8 weeks after baseline is listed below:

- 88 people (91% of those completing the follow-up) who set a goal around losing weight and/eating a healthier diet - 37 of these had lost weight and 56 were trying to be more active.
- 56 people (86%) who set a goal around increasing physical activity – 45 were trying to be more active and 12 had attended a local activity service.
- 12 people (75%) who had set a goal around alcohol – 11 had cut down and one had given up.
- 13 people (72%) who had set a goal around smoking – eight had cut down and four had quit.

Given that the intervention is relatively short and the follow-up reasonably swiftly afterwards, it is positive that so many had already made changes – although using the Stages of Change model it can be anticipated that some will relapse.

WUTC aimed to achieve an increase in awareness of cancer signs and symptoms

People could name, on average, four signs and symptoms of cancer before receiving new information through WUTC. Men were far less knowledgeable than women, with awareness of each sign and symptom listed being around half that of women's. Over 80% of participants agreed that WUTC taught them something new about cancer signs and symptoms.

Participants appreciated learning more about specific signs and symptoms and some felt more confident about approaching their GP if necessary.

WUTC aimed to increase the number of people taking part in the national screening programmes

The majority of people eligible for screening had

participated (ranging from 73% engagement in bowel screening to 85% in breast screening). Six females stated they were not eligible for cervical screening due to having a hysterectomy and two women were unwilling to go due to a history of abuse. However, WUTC did identify 307 potentially needed screens (276 across the three main programmes and 31 eligible for a chest x-ray), leading to 190 screening goals being set. Across all screening programmes, 26 goals could be followed up – of these, nine screens were completed (35% of those which could be followed up) and two appointments had been made:

- 135 women had not attended the cervical cancer they were eligible for. 52% of these set a goal to do so. Seven out of the 10 we could follow-up had taken action, including two completions.
- 52 people had not attended the breast cancer screening they were eligible for. 60% set a goal to do so. Two out of the four we could follow-up had taken action, with one having completed.
- 89 people had not attended the bowel cancer screening they were eligible for. 53% of these set a goal to do so. Two out of the three we could follow-up had completed the screening.
- 134 people who met the eligibility for chest screening had not attended. 23% of these set a goal to complete. Five out of the nine we could follow-up had taken action, including four completions.

Barriers for not attending included lack of time, not thinking it is important as they feel fine at the moment, being embarrassed or lacking the support to go. Interestingly, one man who had been advised to complete a breast screen by his GP was too embarrassed to attend a female orientated clinic.

WUTC aimed to increase signposting to other services (GP/smoking cessation/weight management programme/other services available)

Signposting to other services (GP/smoking cessation/weight management programme/other services available) was used for over half of the people who set a goal, but was most commonly used with smoking cessation:

- Weight and/diet goal - 300 people (43% of those setting a goal) were signposted to weight management.
- Physical activity goal - 206 people (49% of those setting a goal) were signposted to physical activity services.
- Alcohol consumption - 28 people (30% of those setting a goal) were signposted to drug and alcohol services.
- Smoking - 118 people (71% of those setting a goal) were signposted to smoking cessation services.

At baseline, 172 (27%) people (including 78 men and 92 women) had a sign or symptom of cancer but had not seen a GP. Over half of these set a goal to speak to their GP about their symptom and at follow-up, over a third

of these had done so.

Some issues with signposting did emerge. The Leeds lifestyle service that people were being signposted to was unavailable for some of the pilot period. Also, some participants were averse to being signposted to drugs/alcohol services to reduce their drinking as the drugs aspect was stigmatising.

Secondary aim

WUTC aimed to increase awareness of Yorkshire Cancer Research.

The initiative is clearly increasing awareness of Yorkshire Cancer Research:

- 520 people (40%) of all participants had not heard of Yorkshire Cancer Research before participating in WUTC.
- 91% of all participants agreed they would recommend WUTC to friends and family and 85 of those who were followed up (78%) had mentioned WUTC to someone else.
- The WUTC webpage has been viewed 442 times.
- There has been press and social media coverage of the launches in both the community and pharmacy settings, with a total of 433 engagements across Facebook and Twitter.

7.3 Success factors

The qualitative data collected has helped identifying what is working well and why. Key success factors include:

The use of **lay people** (both CHEs and Pharmacy Champions) to deliver the intervention. Their approachable, friendly manner, their ability to relate to participants (empathy) and make them feel comfortable plus their level of knowledge were critical. This helped participants open up and to be receptive to WUTC.

The **settings**. Going to people in the community or in the pharmacies they visit was important (rather than expecting them to attend primary healthcare settings) as was catching people when they were relaxed, willing to talk and not rushed. It was important that the venues ensured privacy.

The organisations delivering WUTC already being **embedded in their communities**. This meant existing trusted relationships (either with community groups, partners or individuals) that otherwise would have taken time to develop could be utilised for WUTC.

Enthusiastic, committed management. Approaching members of the public 'cold,' with high targets to reach is challenging, however the energy and commitment showed by the pharmacy and community management teams was evident and important.

A comprehensive and on-going training package.

Those delivering had much to learn, both in terms of cancer, screening and operationally (inputting data etc.) so the training needed to be thorough.

The **resources** developed by Yorkshire Cancer Research were well presented with the right amount of information. Providing only selected information was appreciated by participants.

The **format** of WUTC was positive as it:

- Managed to combine an evaluation with an intervention
- Was relatively concise – given the wide-ranging objectives
- It was an efficient mechanism to produce personalised follow-ups
- Could operate off-line
- Tailored questions

Table 13. Project aims and measures of achievement

Aim	Achieved?	Additional supporting information
Decrease in behaviours associated with cancer risk	Yes	<p>At baseline, most people set goals:</p> <ul style="list-style-type: none"> • 70% set one or more lifestyle goals • 52% set a weight / diet goal and 31% an activity goal • 10% of alcohol consumers and 49% of smokers set a goal to cut down or quit. <p>Of those who completed follow-up, a majority reported progress:</p> <ul style="list-style-type: none"> • 91% who set a weight / diet goal and 86% who set an activity goal made progress • 75% who set an alcohol goal and 72% who set a smoking goal made progress .
Increase in awareness of cancer signs and symptoms	Yes	<p>At baseline 80% said they had '<i>learnt something new about cancer signs and symptoms.</i>' Awareness was not measured at follow-up.</p>
Increase in people taking part in the national screening programmes	Partly	<p>At baseline, a good proportion of non-attenders set a screening goal, however, low overall numbers of non-attenders took part:</p> <ul style="list-style-type: none"> • 307 non-attenders were identified and 190 goals were set. • The percentage of non-attenders who set a screening goal was; 52% for cervical, 60% for breast, 53% for bowel. <p>Of those who completed follow-up:</p> <ul style="list-style-type: none"> • The percentage of those who set a screening goal and had taken some positive action was; 70% for cervical, 50% for breast, 66% for bowel. • The number of people who had taken up screening was 2 for cervical, 1 for breast, 2 for bowel.
Increase in signposting to other services	Yes	<ul style="list-style-type: none"> • At baseline, over half of people who set a goal were signposted to other services; 43% of those who set a weight management goal, 49% of those who set an activity goal, 30% of those who set an alcohol goal and 71% of those who set a smoking goal. • At baseline, 27% had a sign and symptom of cancer but had not seen a GP. Over half of these were signposted to their GP and at follow-up, a third of these had attended.
Increased awareness of Yorkshire Cancer Research	Yes	<p>40% of participants had not heard of Yorkshire Cancer Research before WUTC. 91% would recommend WUTC to friends/family and felt positive about Yorkshire Cancer Research funding the project.</p>

7.4 Future delivery

Issues to consider going forward are listed below.

Approaching people

- There is a need to minimise the current confusion with NHS health checks. Identifying the right words to describe the WUTC intervention to members of the public is important.
- Saying it is helping Yorkshire Cancer Research by taking part can be an effective motivator. However, we need to be careful people are taking part in a fully informed way.
- Having a diversity of CHEs/Champions (in terms of gender, ethnicity and socio-economic status) is helpful. This seemed particularly evident with South Asian women and, to some extent, men. Future initiatives need to consider this during recruitment.
- The finding that many overweight people think they are a healthy weight, and that this misconception is more common amongst men suggests a lack of awareness that needs to be addressed, particularly amongst men.
- WUTC confirms men are living less healthily than women and other research confirms that men in Yorkshire are more likely to develop and die of cancer than women (PHE, Cancer in Yorkshire and the Humber, 2016 report). Identifying effective strategies to reach men is therefore important. Appendix 9 provides some general recommendations for working with men.
- The evaluated intervention (especially the follow up) was less suited to those who did not speak English, are illiterate or are visually impaired. How to adapt it for this important audience needs considering.
- The intervention needs to either stay at the current length or get shorter. This will help target numbers be reached.

Delivery

- How best to increase the confidence of WUTC Champions in approaching and talking to people from various walks of life and encouraging them to set goals.
- In pharmacies, staff face many challenges to deliver WUTC. It is therefore important to ensure the initiative can be delivered within their normal business remit and that the best pharmacies for the intervention are identified.
- Accuracy of inputted data was not always optimal. This needs addressing in the future to minimise time spent correcting and maximise follow-up opportunities.
- Understanding when it is appropriate to set screening goals needs to be highlighted during training and ongoing support.

- For the follow-up used in this evaluation, smartphones and tablets were the dominant method for electronic completions. This suggests that where an interactive follow-up is sent as part of future initiatives, the questionnaire should be formatted to work across desktop, smartphone and tablet mediums.

Target audience

- Participants often suggested broadening the criteria for WUTC to all adults – or at least those living less healthy lives. This could be considered for the future.
- Mapping of postcodes showed that some participants did not reside in the target areas which may have impacted on prevalence of lifestyle risk factors and screening uptake rates, particularly where participants were from more affluent areas with better health outcomes. Where engagement with those most at risk is of key importance, future initiatives could include target postcode areas as part of the screening criteria for participation or focus delivery in settings where local residents are most likely to visit such as community groups and community hubs and minimise delivery at locations which may attract visitors from outside the area (e.g. sports events and festivals).
- The initiative was successful in facilitating lifestyle change, raising awareness and encouraging early diagnosis. As the initiative did not actively target ‘non-attenders’ of screening, then its ability to improve engagement with screening in that group is limited, although discussions around the importance of screening may help prompt these people when they next receive an invite. Future similar initiatives could incorporate GP targeting of screening non-attenders and referral of these into WUTC.
- Having target numbers can conflict with reaching more disadvantaged communities as these can be more challenging to recruit and require more support to deliver the initiative. This needs to be considered for future rollout to ensure those at greatest risk are targeted.

Follow-up

- The evaluation is now complete and the follow-up questionnaire, as it was, will no longer be distributed. However, it has been identified that this also served to encourage/nudge people to fulfil their goals. Going forward therefore, there is a need to consider a mechanism to still provide this timely nudge.
- A period of six to eight weeks may not be sufficient to change established behaviour patterns or arrange screening appointments. Where future initiatives aim to measure these outcomes at follow-up, a longer period or several follow-up contacts (e.g. at 6, 9 and 12 weeks) should be considered.